## Verification Committee Concerning Hansen's Disease Problem

## **Final Report**

(Summary Version)

March, 2005

Japan Law Foundation

Verification Committee Concerning Hansen's Disease Problem

## Preface

We, the members of the Verification Committee, are now able to publicly issue the "Final Report of the Verification Committee Concerning Hansen's Disease Problem" as a result of our verification task on Hansen's disease problem, which was carried out for more than two and half years. There are a total of 1500 pages consisting of two volumes in that Final Report.

This Task was commissioned by the Ministry of Health, Labour and Welfare. How these results are reflected in our society largely depends on future policies of the Ministry. With this said, looking back at the process of this Task, we can see that this Verification Committee has been a forum of cooperative work and combined wisdom, where various agencies and organizations of the government, groups in society, and various individuals gathered together -even though they had different positions and opinions - to seek the truth concerning unprecedented national-level violations of human rights, namely the Hansen's disease problem, and to prevent future recurrences of such violations. In this sense, the verification was process of reviewing a national policy, which was carried out regardless of the positions and opinions of the parties involved; those who carried out the Task were by no means limited to one certain position, and its role goes far beyond the condemnation of the past. When and only when the concrete process of further reviewing and improvement - that should reveal the facts of the past and clarify the background as well as the causes, consider today's circumstances, and incorporate these findings in our future development of government policies - is implemented, connecting the nation, society, and individual citizens, then the results of our verification shall receive true praise.

Through the process of this Task we were able to meet many who walked along the same path as ours. Not only were there the Committee members who were directly responsible for carrying out the Task process, but also there were many others who took up the Task's work with us indirectly, those who helped us in many difficult situations we found ourselves in, those who expressed high expectations for our Task, and those who gave us constructive criticism concerning the Task. The fact that these many people were found in this country shows a result of the bitter struggles of our predecessors who had worked on this problem; at the same time, it is a result of our contributions (however little it may be) that the members of us, the Verification Committee, has made in creating the society's capability for solving future problems. As the Final Report shows, we were able (even though the work could not been said well to be perfect) to comprehensively and objectively find the past facts, and to make recommendations and proposals for recurrence prevention of similar problems. In addition to the documents included in the Report, twice as much literature as those documents has been prepared and will be publicly disclosed after the completion of this Task. If the Report and these other documents become a driving force toward further problem-solving in the future, one could say that we, the Verification Committee, has laid at least a foundation for a better medical and welfare system for this country. It is our hope that this Task will be regarded as having made progress, by making the problem solution process developed and advanced from a court room toward the society widely, on that process which began with a historical legal decision rendered in May, 2001, on the "Hansen's Disease Government Liability Lawsuit."

The mandate of the Verification Committee ends in March 2005, leaving to the government and the society the task of advancing toward the solution to the problems related to Hansen's disease. Recognizing that we ourselves will be a subject of future verification, we deeply welcome further and ceaseless continuation in the future of the process of solving the problems and making improvements in such a fashion. This summary version has been prepared in order to summarize the achievement of the verification process by the Committee, and to provide an accessible resource to many people who will take over this task in the future. We, too, being held accountable for the results shown in this document, will go beyond this verification and continue to move ahead in that from now on each of us as an individual will go forward towards the solution to the problems.

It is our sincere and constant desire that you, who will take over carrying this torch and move forward, will, in the spirit of our work, use this document as well as the Final Report.

March 1, 2005 Members of the Verification Committee Concerning Hansen's Disease Problem Japan Law Foundation

## Final Report (Summary Version) of the Verification Committee Concerning Hansen's Disease Problem

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?This report has been prepared in such a way that basically each chapter of the Final Report is summarized; however, some chapters are specially summarized by section and/or subsection. The # number appearing at the end of each chapter heading above indicates the corresponding chapter (\_section\_subsection) in the Final Report.

#### **Concerning the "Verification Committee"**

The "Verification Committee Concerning Hansen's Disease Problem" (hereafter, the "Verification Committee") held its first meeting on October 16, 2002, and carried out, for the next two and a half years, the task of "verifying and investigating facts concerning problems involving Hansen's disease." This task was commissioned by the Ministry of Health, Labour and Welfare to the Japan Law Foundation. The purpose of it was stated as follows: "To verify scientifically and historically the reason that the segregation policy was implemented over patients of Hansen's disease for such a long period of time, and the reality of the human-rights violations caused by the policy, from various angles including the medical background, the social background, patient treatment at the sanatoria for Hansen's disease, laws such as the Leprosy Prevention Law, etc. and to make recommendations and proposals to prevent recurrence" (see Attachment "Implementation Modality for the Task of Verification and Investigation of Facts Concerning the Problems Involving Hansen's Disease").

The Verification Committee consisted of a total of 13 members: two former patients of Hansen's disease, four members of the media, two lawyers, one sanatorium director, and four experienced scholars. The Task was done with an additional twenty members of the Research Panel whose job was to investigate, discuss, and prepare reports, all of which were necessary for the verification activities (see Attachments "List of the Verification Committee Members (as of January 2005)" and "List of the Research Panel Members (as of January 2005)"). Meetings were held 26 times thus far, and 13 of these meetings were held as "verification meetings at local sites" at the 13 national Hansen's disease sanatoria across the country. Including these on-site visits, the Verification Committee has visited all 13 national sanatoria in Japan as well as the two private sanatoria and two sanatoria overseas (Korea and Taiwan) in order to carry out thorough verification. Furthermore, the Research Panel held 18 meetings for continuous discussions, and carried out the task of "the survey of the reality of damage concerning Hansen's disease problem."

During that time, in March 2004 (at the half-way point of the project), a mid-term report entitled the "Report of the Verification Committee Concerning Problems Involving Hansen's Disease, FY2003" was published. Further, in FY2004, which was the year of the project's completion, the Drafting Committee was established within the Verification Committee for the purpose of preparing a final report. In July 2004, the Verification Committee published a report called the "Results of the Investigation of the Reality of Damage (Advance Report)," a summary result of the nationwide investigation concerning the reality of damage suffered. In January 2005, prior to the publication of the entire final report, the Committee published two

documents: "(Separate Volume) Survey Report of the Reality of Damage Concerning Hansen's Disease Problem"; and "(Separate Volume) Investigation Report on Fetus Samples and others." In March 2005, all of the verification was compiled and edited into the three-volume final report, including the two separate volumes just mentioned. At the 26<sup>th</sup> meeting held on March 1, the final report was presented to Mr. Hidehisa Otsuji, Minister of Health, Labour and Welfare (see Attachment "Records of the Activities of the Verification Committee and the Research Panel").

## 1. Kumamoto District Court Decision and Truth-Finding #1

### A. Holdings on Disputed Points in the Decision by The Kumamoto District Court

1. Unconstitutionality of the (New) Leprosy Prevention Law\*

"...The segregation requirement in the New Law had already deviated, at the time of its establishment, from a reasonable restriction by public welfare, and its unconstitutionality was already clearly known by, at the latest, 1960..."

2. Illegality, and Intention and/or Negligence, concerning the Implementation of Hansen's Disease Policy Carried Out by the Minister of Health and Welfare

"...The Minister of Health and Welfare ... is to be held legally liable for having irresponsibly allowing the segregation to continue without changing the segregation policy fundamentally or taking appropriate actions required to do so... and for allowing the society to believe that Hansen's disease was a horrible infectious disease and its patients were dangerous that needed to be isolated. It is thus appropriate, on the basis of the National Redress Law, to consider illegal his official action as a civil servant functioning as the Minister of Health and Welfare. In 1960, the Minister of Health and Welfare was either fully aware of enough medical knowledge and information necessary to determine the necessity of segregation, or able to easily obtain such knowledge and information; further, the facts of discrimination and prejudice against Hansen's disease patients and former patients of this disease were also easily accessible to him. Therefore, the Court is able to find easily that there was negligence of the Minister of Health and Welfare.

3. Illegality, and Intention and/or Negligence, Based on the National Redress Law, concerning the Act of Legislating the Law by Members of the Diet

"...Considering the severity of human-rights violations due to the continued existence of the segregation requirement under the New Law, as well as the necessity of judicial remedy for the violations, as this was a case extremely special, exceptional, and hardly imaginable elsewhere, the lack of legislative action by members of the Diet by not eliminating or revising, even after 1965, the segregation requirement under the New Law was illegal in light of the National Redress Law.

<sup>\*</sup> (Note by Translator) In this report, there were two Acts named as "Leprosy Prevention Law": one is enacted in 1931; and the other was its revised version enacted in 1953. For the translation purpose of the report, such an indicative word as "Former" is sometimes added for the 1931 Act, and "New" for the 1953 Act, as appropriate, while it is easy in Japanese to determine whether a description indicates the 1931 Act or the 1953 Act even without mentioning its enacted year because the name of 1931 Act is described in Chinese characters, and that of 1953 Act in part in *Hiragana*.

#### 4. Damage

"... Concerning the damage suffered through segregation ... it is possible to find certain common factors... where certain time period is specified... The difference of the extent of damage suffered among individual plaintiffs does not put the defendant at a disadvantage, so long as the amount of damages is calculated conservatively, taking into consideration those cases of less severe damage. Damage of pains and sufferings, which are due to the facts that the plaintiffs were discriminated against in various ways... and that the plaintiffs were put in such a position, should be figured out as damage, and certain common factors can also be found in this regard.

### 5. Statute of Limitation (Expiration Period)

"...As the damage suffered from the illegal actions in this case are from the violation of the right to live peacefully in society, and those damage had been caused continuously and cumulatively until the repeal of the New Law, the amount of damages cannot be calculated appropriately without holistically evaluating, at the time when the illegal actions ended, the lifetime damage to entire human life as a whole. Because of these special characters of the illegal actions and the damage in this case, it is appropriate to interpret the 'time of tort,' which is the beginning of the statute of limitation (expiration period), as the time of the repeal of the New Law."

### B. Significance of the Decision by The Kumamoto District Court

In the following poem, a plaintiff expressed their joy and emotion upon hearing the decision of the court.

The sun has shone. For ninety years In a long, long darkness A flash of light shone Powerfully and clearly Crushing a solid boulder Light shone I no longer have to look down I can walk with confidence In the light I no longer have to look down any more The sun is shining

## C. District Court's Decision and Truth-Finding

The "Finding" section of the district court's decision, except for the "Holding" part, consists of two parts: "Medical Knowledge and Information on Hansen's Disease and Its Transition" and "The Transition of Japan's Policy on Hansen's Disease." The latter part consists of four sections: (1) "Situation before the World War II") (the enactment of the "Matter concerning the Prevention of Leprosy, "the establishment of sanatoria, the authorization of disciplinary restriction and detention, carrying out of sterilization, the first sanatoria expansion project, the expansion of the range of patients to be placed in sanatoria, the enactment of the Former Law, "the Policy to Eliminate Leprosy," establishment of new sanatoria, the Campaigns for Leprosy-Free Prefectures);

(2) "Situation After the World War II Until the Enactment of the New Law" (exposure of the Special Ward affair at Kuryu Rakusen En, the enactment of the Eugenic Protection Law, Promin budget-making, the second sanatoria expansion project after the World War II and the tougher policy of patients' confinement, a murder at Kuryu Rakusen En and its effects, speeches by three sanatoria directors, Battle against the Prevention Law,, written response of the Prime Minister to questions from a House of Representative member Tamotsu Hasegawa, discussion in the Diet on the New Law, interpretation of the phrase "patients that may be contagious");

(3) "Situation After the Enactment of the New Law" (provisions in administrative notices after the enactment of the New Law, development of a campaign to revise the New Law, discharge from a sanatorium, the restriction on outings, eugenic policy, patients' work, transition of living conditions at sanatoria, medical care<sup>†</sup> at medical facilities other than sanatoria, process leading to the repeal of the New Law); and

(4) "Societal Discrimination and Prejudice against Hansen's Disease Patients" (conventional discrimination and prejudice from the past, discrimination and prejudice prior to the World War II after the Leprosy-Free-Prefecture Campaign, discrimination and prejudice after the World War II, residual disability and alias at sanatoria, manifestation of discrimination and prejudice).

This is the court decision that took seriously the plaintiff's case head-on, and admirably grasped the framework of the historical facts on the policy on Hansen's disease during 90 years

However, structural limitations within the judicial system being taken into account, it is a fact that many problems were left from the perspective of truth-finding and prevention of recurrence. For instance, why was it that the compulsory segregation

<sup>&</sup>lt;sup>†</sup> (Note by Translator) For the purpose of the translation of the report, the word "treatment" indicates not only medical clinical settings, but rather indicates a variety of types of care and other living conditions as a whole (basically in a sanatorium), corresponding to the Japanese word "*Shoguu*." Contrastingly, words such as "medical care," "medical attendance," or "medical treatment" is used to indicates some medical clinical context, corresponding to the Japanese word "*Chiryou*."

policy on Hansen's disease, which was unconstitutional and illegal, was not abolished even after the World War II but was rather reinforced more? And why was the 1953 law not repealed until 1996? These questions were left to later examinations. An in-depth study of the responsibilities of various fields involved in the compulsory segregation policy-not just their legal responsibilities in a very limited sense but responsibilities in a larger sense from the point of view of preventing recurrence-was also left as a challenge.

In addition, there was a limitation referred to as "Resolution within Three-years No Matter What," unique to that litigation. As a result, because the lawsuit focused its attention on proving common damage, clarification on individuals' damage was not always sufficient, at least on the surface. The damage issue in Okinawa during the period between the World War II and its reversion to Japan was also left to be analyzed later. This is because the decision of The Kumamoto District Court stated the following opinion.

"The policy on Hansen's disease in Okinawa prior to its reversion to Japan underwent a different process than the mainland's policy on Hansen's disease; while there is much in common in both legal systems themselves, the evidence is not necessarily sufficient concerning the implementation of the segregation requirement and the reality of permission to be discharged. It cannot be said that there is enough evidence to prove that the damage suffered in Okinawa prior to the islands' reversion to Japan can be equated with those of the mainland in the same time period. Hence, ... the court has decided that: the damage prior to the reversion as individual damage are not qualified to compensation in this lawsuit; rather, only the damage suffered after Okinawa's reversion to Japan are qualified to compensation."

Also, there was a similar situation with respect to the elucidation of the structure of discrimination and prejudice. While, this decision states the following: "...The discrimination and prejudice generated by the policy on Hansen's disease, such as the Campaign for Leprosy-Free Prefectures, is clearly different in nature as compared to those that had existed earlier.... It is no exaggeration to say that the discrimination and prejudice against Hansen's disease patients, which still continues today, originated there," nevertheless many points of this campaign were left to be analyzed later.

However, a question being asked of whether the truth can be found and recurrence prevented without exploring these questions, our answer should be clearly negative.

## 2. View of "Leprosy" in the Early-Modern<sup>‡</sup> Age and How It Was Formed-1907 "Matter concerning the Prevention of Leprosy" #2 (\_1)

### A. Questions

"Leprosy" was mainly considered to be a sickness caused as a punishment for sin in the Medieval Age; as history shifted from the Medieval to Early-Modern Ages, the disease was considered to be hereditary or "in the family."; it is also pointed out in the existing research of history that this disease has been thought of as an infectious disease since the Modern Age. As a historical setting for discrimination against Hansen's disease in the Modern Age, we discuss the following three aspects of discrimination in the Early-Modern Age.

The first question is of since when this idea that "leprosy" is in the family has been believed in the Early-Modern Age. The second is the question of how such discriminatory ideas as "punishment for evil deeds" and "karma disease" has developed in light of the "in-the-family" belief. The third is the question of how "leprosy" patients actually lived their daily life under such views of "leprosy" and discriminatory belief.

#### **B.** Analysis in Medical Literature

The medical literature in the Edo Period -which we investigated- includes specialized books written for physicians as well as more common, family-oriented medical books, and secret books and documents handed down through generations in temples and shrines. We investigated about 80 volumes containing statements regarding "leprosy." The central etiology theory seen there is that leprosy is infectious among blood relatives, but there are also other theories such as food poisoning and an endemic disease. All these theories can be seen as originating in Chinese medical writing, but a characteristic of Japanese early-modern medicine is seen in the fact that these particular theories were chosen among a wide variety of etiological explanations developed by Chinese medicine. Here, we analyze the background of these theories and its relationship to the discriminatory belief against "leprosy."

#### 1. Blood Line Theory

In medical literature, expressions like "leprosy" as "family line" hardly ever appears;

<sup>&</sup>lt;sup>‡</sup> (Note by Translator) Generally, as matter of terminology of period division of Japanese history, a Japanese term "*Kinsei*" is used for a period that largely amounts to the "Edo Period"(1603-1867), and "*Kindai*" for a certain period starting with the end of the "Edo Period." For the translation purpose of this report, a word "Early-Modern" indicates "*Kinsei*," and "Modern" indicates "*Kindai*."

instead, the expression "blood line" was used. This is because it was believed that a person born in the bloodline of "leprosy" got "infected" with "leprosy" from a blood relative who suffered from "leprosy." Such a belief is not seen in Chinese medicine and is unique to early-modern medicine in Japan, originating in the second half of the seventeenth century. Because it was considered to be a disease of blood line, "leprosy" was regarded as an embarrassment for the entire family.

Several factors helped this theory to be established. First, because social and economic stability reduced the percentage of patients compared to the Medieval Ages, onset of this disease within families -those who grew up in the same environment and those in close contact with patients from an early age- were noticed more. Another factor was syphilis, which had become very common in the Edo Period. Not only is syphilis a venereal infectious disease, but also it was widely believed that this disease could be inherited prior to one's birth from a blood relative as an "inherited poison." It appears that this pathological belief of syphilis had influence on "leprosy" as well. A third factor is that, since the 17<sup>th</sup> century, the sense of "family" or "household" had spread all the way down to common people, and they began to see everything in terms of one's "family" or "household" framework.

#### 2. Food Poisoning Theory

Onset of the disease in those patients without blood line required another explanation, such as food poisoning and an endemic factor. According to the food poisoning theory, the body could get worse by eating an excessive amount of fish or animal meat, causing the body to be more susceptible to "leprosy." This laid grounds for criticizing the discriminatory belief of family line "leprosy," and, at the same time, it sometimes led to discrimination against those in fishing-villages and other poor communities where people had no choice but to eat fish and animal meats.

#### 3. Endemic Theory

The endemic theory is the belief that the disease is more likely to occur in areas with certain geographical features, water quality, and/or climate. This too was a view used against the family/hereditary theory and, at the same time, led to discrimination against those living in certain environments, as the view reinforced discrimination against so-called "leprosy" village.

### C. Analysis from Various Regional Sources

Here we present our analysis of how "lepers" lived in the Edo Period, obtained from various regional sources. "Lepers" in the Edo Period can be generally classified into four groups: those living the lifestyle dating back to a Medieval outcaste "non-human" those incorporated into the Early-Modern outcaste system as the class "leper"; those

who would drift around or become beggars; and those who were taken care of at home by family or community.

1. Lifestyle passed down from a Medieval Outcaste "Non-Human"

It is clearly known from general research on medieval history that there were "lepers" living in medieval outcaste "non-human" facilities. Those who share genealogy with them include the "lepers" in Monoyoshimura in Early-Modern Kyoto, and those in Nara at Nishiyama Komyo In, and Kitayama Ju Hachi Kenko. These patients made their living in these places of worship established in the Medieval Ages, begging for alms as members of a lowly religious class. However, these facilities were open spaces that allowed the general public to visit them, so they are different from modern isolation facilities. Patients that were able to live this way were very few.

2. Incorporated into the Early-Modern Outcaste System as the Class "Leper"

In contrast to the lifestyle as members of the lower-ranked religious class described above, who had carried on the Medieval system, there was another form, a class called "leper" created anew by the Early-Modern Age authority. This is a case where a disease, which is by nature merely a temporary state of being, was considered a fixed "class."

Geographically, this was seen in certain districts in Tohoku (northeastern Japan), the Kaga Domain, and some domains in Kyushu. The class was placed below the rank called "Eta,"(extreme filth) and they often served the members of the Eta rank. It is possible that such a rank structure may have created a climate that would lead to the biased notion in modern times that Hansen's disease was more common in "Buraku," the villages that are discriminated against.

#### 3. Those Who Left Home

Some tried hot-spring treatment, and others made pilgrimages. As factors encouraging these travelers, it can be said that; in the Edo Period, as streets and overnight accommodations were improved, and a system of "sending patients to villages" was also completely established, people traveled more; and the business promotion policies of various domains created many hot spring sites. These hot springs had outcaste "non human" baths where patients could bathe free of charge.

### 4. Those Who Stayed Home

Not too many people actually lived in the ways described above. The basic lifestyle of "lepers" in the Edo Period seems to be "work as long as possible at home"; this is considered similar to that in such certain period of Modern times as prior to the development of compulsory segregation.

With these various forms of living, which one a particular patient chose, seems to have been dependent upon the region, class, sense of family or household, economic situation, and gender.

#### **D.** Analysis of Literature

We also analyzed attitudes toward "leprosy," mainly in urban areas during the Edo Period, through the transition of the legenda "Shintoku Maru." Between the Medieval Ages and the early Edo period, the exclusion of "lepers" based on the belief of "unclean (filth)" was found among aristocrats of the capital but not among common people. For common people, whether or not to *make* "lepers" leave home was determined by their economic ability to care for such a patient when the patient became unable to be labor resources. It is seen that common people's prejudice was based on a sense of hatred toward the appearance of the patients.

It was during the latter half of the 17<sup>th</sup> century when "leprosy" began to be emphasized as "karma disease." This was when terms such as "exposed karma," "divine-judgment disease," and "karma disease" gained popularity. This coincides with the time when people began to regard "leprosy" as a family-line disease and as an embarrassment to the family. The karma-disease theory appears to have been reinforced by this family-line belief.

#### **E.** Conclusion

Since the life of a "leper" in the Edo Period varied significantly according to the geographical location, rank, sense of family, economic conditions, and gender, it is difficult to provide a generalized description. The Edo Period was a time in which beliefs about diseases and patient treatment from the medieval times changed to those of the Early-Modern period. It was also a period of transition toward the unification of them in which the central government and subordinate domains (the shogunate system") were established as a unified system and communication means saw progress. It seems that consensus in beliefs on diseases and patient treatment was not aggressively promoted until the shift to government of the modern nation

Medieval and early-modern societies made the accommodation of "lepers" in a religious facility such as Kitayama Ju Hachi Kenko, and allowed them to beg for alms, partly as a coexistence system based on productivity in the medieval and early-modern society. However, in the historical stage of the Modern Period, compulsory relocation to isolation facilities is totally incompatible with the productivity, awareness of human rights, and the level of advancement in medical science.

Similarly, it is meaningless to compare the life of "lepers" in the Early-Modern Period with the life of Hansen's disease patients in sanatoria of the Modern and Contemporary history and discuss which is "more miserable" or "discriminatory" while ignoring the historical development process. Nevertheless, there is a fact that one must ponder very seriously: it is the fact that, despite all the differences in the context of historical development, the modern nation moved, from having allowed patients in early-modern ages to live according to their circumstances of family, regions, and communities, toward calling "leprosy" a fearful infectious disease, continuing compulsory confinement, and so convincing and unifying people's minds and the social system as to reinforce the absolute segregation of patients of the disease.

# **3.** View of Hansen's Disease in the Modern Age-1907 "Matter concerning the Prevention of Leprosy" #2 (\_2)

## A. View of Hansen's Disease as Seen in Medical Literature Prior to the Segregation Policy

Masafumi Goto, who managed Kihai Hospital, which was founded in the early Meiji Era and was well-known for being a hospital exclusively for Hansen's disease, published the "Kihai Hospital Medical Journal" in 1877, and his son Masanao published "Self-Treatment of Difficult Diseases" in 1882. From these treatises, it appears that empirically they were aware that it was possible that Hansen's disease might be transmitted although it is unclear whether or not Goto was aware of the discovery of the leprosy bacterium by Armauer Hansen.

After them, the following books were published since the 1880s, revealing the view that understood the onset of Hansen's disease as infection. based on the discovery of the leprosy bacterium by A. Hansen These volumes were "A New Theory of Leprosy Treatment" by Hiroshi Kobayashi (1884), "Lessons on Leprosy Treatment" by Gentoku Matsuda (1886), "Leprosy Story for the General Public" by Kichibei Mori (1887), "How to Grow Remedy Medicine for Leprosy" by Kotaro Ohki (1892), and "Leper's Autobiography" by the same author (1895).

However, on the other hand, there were many medical books based on traditional hereditary theory; some of them, while even admitting infection, did not deny the hereditary factor.

#### B. Beliefs on Hansen's Disease among the Common People

The literary character "Takahashi Oden" from the beginning of the Meiji Period reveals how the general public of those days viewed Hansen's disease; the hereditary theory was widely held. The case on which the story was based was a murder case in which a woman named Den Takahashi was arrested in 1876. Around just after the time of her execution for a murder she committed (1879), the character "Takahashi Oden" began to appear in many literary works. In these, her husband suffers from Hansen's disease. "Takahashi Oden Yasha Story" written by Robun Kanagaki in 1879, "Her Name Is Takahashi the She-Devil A Short Story of Tokyo" by Kisen Okamoto, and "Tojiawase Oden no Kanafumi" by Mokuami Kawatake all revealed the belief that Hansen's disease was hereditary.

Further, "Takahashi Oden" written by Senzaburo Suzuki in 1921 described a vulgar belief that Hansen's disease was prevalent in discriminated villages "Buraku", but this was a theory maintaining that Hansen's disease was more prevalent in these villages due to "marriages among relatives" since discrimination did not often allow these villagers to find spouses outside the community (hence assuming that Hansen's disease was hereditary). This type of belief existed as vulgar belief, conveniently used to justify avoidance of marriage to someone in those discriminated villages ("Buraku.") With such vulgar belief in the background, Zensei Hospital made an inquiry titled, "Study and Questionnaires of Special Villages (Buraku) with Leprosy" on May 12, 1916, to each prefecture and Hokkaido.

## 4. Start of the Compulsory Segregation Policy and Actual Conditions of Sanatoria-1907 "Case concerning the Prevention of Leprosy" #2 (\_3)

#### A. Background for the Law, "Matter concerning the Prevention of Leprosy"

In 1907, the law, "Matter concerning the Prevention of Leprosy" was issued; there were two motives that led the government to make the decision to segregate Hansen's disease patients. First, in the World Leprosy Conference held in Berlin in 1897, Hansen's disease was confirmed to be an infectious disease and that isolation was a good way for its prevention. Second, new treaties came into force in 1899 due to revisions of former treaties between Japan, the U.S., and the European nations, initiating "integrated living on the mainland (the policy of allowing foreign citizens to live anywhere, not only in designated locations)."

To Japan, which had won the Sino-Japanese War, and had succeeded in the revision of those treaties, however, the fact that the country had more than 30,000 patients-as many as in Asian and African colonies-was nothing but national disgrace.

#### B. Process toward the Law "Matter concerning the Prevention of Leprosy"

The first serious national-level debate on a policy to prevent Hansen's disease in the Imperial Parliament took place in March 1899, in the 13<sup>th</sup> Session of the House of Representatives. This was just before the government was to commence "integrated living." The call for strict control of Hansen's disease patients was to continue in the parliament from the standpoint of national disgrace, but among those pushing for more control, one particular individual who was gaining power was Kensuke Mitsuda, who had close connection with the political and administrative communities through his acquaintance with Eiichi Shibusawa. The government distinguished Hansen's disease from acute contagious diseases and moved toward isolating its patients under a separate law, not the Infectious Disease Prevention Law.

#### C. Enactment of the Law "Matter concerning the Prevention of Leprosy"

In 1907, the Law, "Matter concerning the Prevention of Leprosy" was enacted to isolate mainly those homeless patients in society with little or no financial power. In accordance with this law, the country was divided up into five regions, a sanatorium was established in each region under the grouping of prefectures, and the segregation of homeless patients began: Region 1 with Zensei Hospital (Tokyo, 350 patient capacity); Region 2 with Hokubu Rest Center (Aomori, 100 patient capacity); Region 3 with Hokajima Rest Center (Osaka, 300 patient capacity); Region 4 with Region 4

Sanatorium (the name was changed to Oshima Sanatorium in 1910, Kagawa, 170 patient capacity); and Region 5 with Kyushu Leprosy Sanatorium (the name was changed to Kyushu Sanatorium in 1911, Kumamoto, 180 patient capacity). Kensuke Mitsuda became a doctor at Zensei Hospital.

#### **D.** Advent of Disciplinary Restriction and Detainment Rules

The fact that the national policy on Hansen's disease in Japan began with the segregation of financially challenged homeless patients had considerable influence on the role of sanatoria later. At first, former police officers were hired as center directors and staff members because former policemen were considered to be appropriate people to manage homeless patients. In 1916, the first revision of the law took effect, that clearly put those under the disciplinary restriction and detainment rules, those who were placed in a sanatorium.

Meanwhile, beginning in 1915, under the direction of Kensuke Mitsuda, who had become the director at Zensei Hospital, the male patients placed in the sanatorium were sterilized; this practice spread to other sanatoria as well. Further, in order to compensate for the lack of staff members, the patients were forced to work. The patient labor required was a wide variety of considerably hard work, including accompanying and caring for advanced patients, washing and cleaning of gauze and bandages, cleaning the facility, carrying and taking out human wastes, giving haircuts, sewing, woodwork, and dirt work.

#### **E.** Toward Absolute Segregation

On June 27, 1916, the second Ohkuma Administration set up a Health and Hygiene Study Committee under the Ministry of the Interior in pursuit of a new public health policy for the country, in view of an increasing population after the First World War. Part 4 of the policy dealt with Hansen's disease. Here, the policy was changed to absolute and total segregation.

The policy of absolute segregation was made specifically on September 14, 1921 by the "Fundamental Preventive Measures of Leprosy," a resolution of the Health and Hygiene Study Committee. This report proposed the following: expansion and addition of public sanatoria and new establishment of national sanatoria; nationally or municipally funded establishment of free treatment districts for patients with financial resources; prohibition of patient employment in jobs where infection can occur; national and public money used to pay some of the living expenses of patients who could not otherwise live due to segregation; and abortion when requested by the patient ("Matter concerning the Prevention of Leprosy," edited by the Public Health Bureau of the Ministry of the Interior, 1920). At first, the number of patients to be isolated in national and public sanatoria was targeted to be about 10,000 (in June, 1921, this was revised to 5000 in 10 years due to the post-war depression). The policy of establishing new national sanatoria was becoming more solid (7<sup>th</sup> and 8<sup>th</sup> Report of the Health and Hygiene Study Committee, 1924).

In 1929, in the 56<sup>th</sup> Session of Imperial Parliament, a revised version of the law "Matter concerning the Prevention of Leprosy" was passed, incorporating the establishment of national sanatoria.

#### F. Actual Conditions of Private Sanatoria

The actual conditions of private sanatoria were studied by analyzing a report by Keikou. Honda of the Shinshu Otani denomination, dated 1913, with the permission of his family descendents. It reveals the reality of private sanatoria in the early 1910s. These private institutions appeared to support and complement public sanatoria.

## 5. "Leprosy Prevention Law" of 1931-Reasons and Responsibility for Stricter Control of the Compulsory Segregation and Confinement #3

### A. Enactment of "(Former) Leprosy Prevention Law"

The Leprosy Prevention Association was founded in 1931, and the 59<sup>th</sup> Session of Imperial Parliament significantly revised the law "Matter concerning the Prevention of Leprosy," leading to the enactment of the "Leprosy Prevention Law." At this point a law of absolute segregation took effect. The first national sanatorium, Nagashima Aisei En, was also opened. Thus, in 1931, Japan's policy on Hansen's disease reached the point of absolute segregation. In September of the same year, the "Ryujo-ko Affair" led Japan to the Manchurian Incident, and in July 1937, the Marco Polo Bridge Incident initiated a full-blown war between Japan and China. Then, in December 1941, the United States and the United Kingdom also entered the war. Hence, the "Leprosy Prevention Law" was established immediately before the 15-year-period of war in which Japan fought in Asia and the Pacific; it was implemented during the 15-year war period. In the midst of the prolonged war period, the policy on Hansen's disease was also placed within the framework of a eugenic policy to create better citizens who were superior physically and psychologically.

## **B.** Public Health Policy and Hansen's Disease Policy for the 15-Year-Wartime Period

Absolute segregation brought about a social movement to sanatoria; the Oshima Incident, the Hokajima Incident, and the Nagashima Incident occurred in a short period of time. To suppress patients' movement, in 1938, "Special Wards," i.e. Heavy-Security Cells, were built in Kuryu Rakusen En.

# C. "Citizen Eugenic Law" and a Revision Proposal of the "Leprosy Prevention Law"

In March 1940, the second Konoe Fumimaro administration proposed at 75<sup>th</sup> session of Imperial Parliament a "Citizen Eugenic Law," which stipulated the implementation of sterilization surgery on sick and disabled people if the sickness or handicap was considered hereditary and made other sterilization surgery illegal. Obviously, patients with Hansen's disease would not be covered according to this law. Hence, the administration decided that sterilization of patients with Hansen's disease would be stipulated in a revised version of the "(Former) Leprosy Prevention Law." However, while the "Citizen Eugenic Law" was passed, the revision proposal for the "(Former)

Leprosy Prevention Law" was not as incomplete deliberation. After that, however, the sterilization of patients with Hansen's disease continued, with the following argument: the "Citizen Eugenic Law" states that "surgery and radiation treatment that would disable reproduction for no reason shall not be performed," but sterilization of patients with Hansen's disease does not fall under this law since such surgery is NOT "for no reason." The reason that sterilization of patients with Hansen's disease continued despite such a twisted interpretation of the law was, for one, a belief that certain body types are easily infected with Hansen's disease and that sterilization would eliminate the heredity of such body types.

## 6. Hansen's Disease Policy for Japan by GHQ-1953 "Leprosy Prevention Law" #4 (\_1)

#### A. Method of Analysis

For the analysis of this section, we first completed the task of creating text files of GHQ (General Headquarters of the Allied Forces) documents related to Hansen's disease stored as files (microfiche) in the National Library of the Diet Constitutional Government Resources Room (Leprosy-Japan: PHW04217-04224, Leprosy-Korea: PHW03078-03081, Leprosy-Ryukyu: PHW03088-03089). The documents totaled 1021 pages (Japan: 641, Korea: 288, and Ryukyu: 92). Excluding meaningless articles on other issues and illegible documents, Leprosy-Japan had 317 pages in English and 284 in Japanese. Leprosy-Korea had 282 pages, all in English, and Leprosy-Ryukyu had 92 pages, again all in English. There were not many memoranda for records reflecting the occupation policy of the GHQ/PHW (General Headquarters Public Health and Welfare Section), but there were a lot of letters and business documents exchanged as references for policies related to Hansen's disease. By analyzing their contents, we were able to estimate the involvement of the GHQ/PHW. Based on these documents, we verified the following points concerning GHQ's policy on Hansen's disease under their occupation of Japan.

## **B.** Statistics on the Number of Patients at Hansen's Disease Sanatoria across the Country, as Counted by the GHQ/PHW

On a list dated September 15, 1945, it was reported that the total number of patients in the 13 sanatoria was 10,411. In November 1946, the total was 8510, and on August 1, 1947, the total was 7931.

### C. Conditions of the Sanatoria Observed by the GHQ/PHW

Knight, a tuberculosis consultant, visited the Oshima Seishou En in Kagawa Prefecture in August 1947; and he reported the following: "The facility at this sanatorium is in extremely good condition, and the laboratory equipment is excellent.... The social welfare of the patients is very appropriately cared for." In 1949 Johnson participated in the Shikoku district physicians' meeting, and he visited Oshima Seishou En and Nagashima Aisei En on this occasion. He reported that 49 out of the 648 patients in Oshima Seishou En and 132 out of the 1480 patients in Nagashima Aisei En were Korean citizens and that they were requesting treatment as foreign nationals. In October 1949, Morton, Stolar, and Strode visited the Tama Zensho En of Tokyo. At this time, when they were meeting with the staff of the sanatorium, Stolar brought up the fact that the International (Leprosy) Association was going to rename leprosy "Hansen's disease." This interested the participants from the Japanese side. It was pointed out that in Hawaii, the term "Hansen's disease" was already used in public documents.

#### **D.** Promotion to Popularize Promin as a Curative Medicine for Patients

Among the documents studied in this analysis, there was a report of the University of Tokyo, dated June 1948, that dealt with medical treatment with Promin. It was verified that in 1948, Promin was used as a curative medicine for Hansen's disease in Japan. At the time, Promin was manufactured at three pharmaceutical companies in the country, but the supply was insufficient for the demand. It was reported that the desire was to procure180 kg of the medicine from the United States. In 1949, Kellersberger of the American Mission to Lepers wrote to General McArthur, urging him to "gain interest in medical treatment of lepers using chemical medicines such as Promin as many requests are coming from Japan." This letter was forwarded to the PHW, and there was a reply by Sams, stating the following: "SCAP is very much interested in Japanese patients of leprosy. Today, most medical treatment at Japanese sanatoria is by Promin. While the medicine is not sufficiently supplied at present, the supply will be sufficient in the near future. The Japanese government has appropriated 470 million yen from the budget for national leprosy sanatoria; 50 million yen out of that amount will be spent to buy Promin. Some sanatoria suffered damage in the war, but they are efficiently managed, and the patients are receiving appropriate care."

## **E.** Promotion to Return Japanese Researchers to the International Leprosy Association

After the start of the Second World War, Japanese researchers virtually had no choice but to suspend all their international activities; even after the war, during the occupation of the Allied Forces, foreign travels by Japanese were severely restricted, and participation in international conferences was fundamentally impossible. The International Leprosy Association made efforts by contacting various areas to have Japanese researchers return to the Association and allow them to contribute their papers for the academic journal of the Association.

Sams wrote: "Dr. Kitamura of the University of Tokyo is reportedly willing to accept the position of contributing editor. Dr. Mitsuda of Nagashima Aisei En is the authority in this field in Japan although I have not personally met him. I believe that he is a first-rate person. All of these men can read and write English. I request that the International Leprosy Association permit the Japan Leprosy Association to be its member. SCAP considers this desirable."

## F. Academic Research Support of Pure Cultivation of Leprosy Bacillus by Japanese and American Researchers

In the 1940s and 50s, Japanese and American researchers were working on artificial cultivation, and the PHW was providing academic support as an intermediary between the researchers of the two countries. In addition, in a letter written in 1949, Sams interestingly wrote "leprosy is not a major problem in public health in Japan."

#### G. Treatment of Hansen's Disease Patients with Foreign Citizenship

Sanatoria for Hansen's diseases in those days did not have only Japanese nationals as patients; some foreign nationals were there, also. In 1947, a woman living in the United States inquired about her son living in a sanatorium in Japan. Sams replied to her: "I have verified that the person you inquired about lives at a sanatorium in Gunma prefecture. The laws of the United States do not permit lepers to enter the country, but exceptions may be granted in special cases such as spouses of American soldiers." Also, patients in Okinawa and the Amami islands, although they are not foreign nationals, needed special consideration for transfer as the mode of the occupation was different in these regions; the PHW was involved in their official handling.

#### H. Hansen's Disease Policy for Japan by GHQ

The biggest and most urgent concerns of the PHW of GHQ were the prevention of digestive-system contagious diseases such as tuberculosis, dysentery, and typhoid, as well as venereal diseases. Because the Hansen's disease patients were under the absolute segregation, there was little fear that the number of patients would drastically increase, and it is undeniable that the PHW did not have a high level of interest in this matter.

The PHW recognized the effect of absolute segregation in its report of June 1949. Sams, the Section's director, highly esteemed Kensuke Mitsuda, as he wrote in a September 1949, letter: "I have not met him personally, but he is a first-rate person and is accepted by Japanese as the authority." In June 1950, he wrote about his satisfaction with Japan's national sanatoria for Hansen's disease: "they are strategically located so that no patients in any regions would have to suffer because they cannot be admitted."

The PHW and Sams had the pragmatic view that Japan's problem with Hansen's disease would be resolved by patient segregation and Promin; consequently, it appears that they did not focus their attention on human-rights violations arising from the segregation policy. If one considers the conditions in Amami and Okinawa, based on the fact that concerns for human rights were non-existent for Hansen's disease patients under "democratization," it is understandable that GHQ, as a part of the occupation policy in the mainland at the time, affirmed the Japanese policy of segregation.

Additionally, although this series of documents do not show it, there seemed to be another reason for GHQ to allow the segregation policy. It was their concern for a trend towards a self-governing movement of the residents of the sanatoria. A set of documents stored in Hoshizuka Keiai En contains some evidence of this.

Hoshizuka Keiai En was a leading sanatorium in calling for a timely post-war national-level unification of self-governing associations, and GHQ suspected that the Communist Party was behind this trend. GHQ cited unrest among the residents as an excuse to interfere, and the residents' self-governing association at Hoshizuka Keiai En had no choice but to be dissolved.

As seen in this incident, GHQ heightened its precaution against any trends of movement toward residents' self-governing associations at sanatoria. GHQ was rather passive concerning requests made by these self-governing associations; requests, such as improvement in treatment at the sanatoria and even the elimination of the compulsory segregation policy. This conforms with the fact that GHQ's "democratization" policy included their anti-Communist policy as well. The policy on Hansen's disease was also within GHQ's framework of "democratization."

#### I. Conclusion

As seen above, the documents of the GHQ/PHW analyzed this time show us the following: GHQ's interest in Hansen's disease was relatively low, due to thinking that Promin given in isolation would resolve the problem. Further, analysis of documents from that time tells us that GHQ's precaution toward self-governing associations was very strong, ignoring voices requesting better treatment at these sanatoria. From these two points, we conclude that GHQ did not have any intention in revising Japan's compulsory segregation policy of Hansen's disease patients.

## 7. Reasons and Responsibility for Stricter Control of Compulsory Segregation-1953 "Leprosy Prevention Law" #4 (\_2)

#### A. Basic Characteristics of the "(New) Leprosy Prevention Law"

A curious fact that attracts attention concerning the policy on Hansen's disease after Japan lost the war is that the confinement of "all patients" was achieved after the war, not before. There was also a major change in who would carry out this compulsory confinement. Certainly, there was conflict between the "new bureaucrats" of the Ministry of Health and Welfare such as Ryutaro Higashi, who took over medical and welfare policies under the new Constitution, and the directors of the sanatoria; however, such opposition was just a "storm in a teacup." Overall, the government, with the balance between these opposing parties, insisted on and completely carried out the confinement policy of "all patients." "Release due to improvement" had not been contradictory to the compulsory segregation policy, either. As the "subjects" called patients in medicine and welfare began to be treated as "objective beings" or "objects," the concepts of a "civilized nation" and "welfare nation" under the new Constitution of Japan were connected with the confinement of "all patients" to "national" sanatoria. As a result, the advancement in "medical care" under the assumption of the "all-patients" confinement policy led the country, not to the elimination of the policy, but (quite the contrary) to tighter enforcement of the policy. In short, even under the new Constitution of Japan, the "national" sanatoria were still places of "rejection from citizens" to those who lived there. They did not possess the basic human rights guaranteed by the Constitution but were rather victims of the "new and bright Japan" and the "healthy, sickness-free Japan." After the war, various opposition groups such as the All-Japan National Leprosaria Patients' Association organized protests against the national policy, but the sanatorium directors did not even acknowledge the rights of the patients, attempting to completely silence any community opposition by keeping the patients as objects of pity and compassion. In order to maintain and tighten compulsory segregation, the physicians who were the directors of these sanatoria-they were specialized doctors treating Hansen's disease patients-not only compromised their responsibility of providing accurate medical information to society but also promoted fear and prejudice among the citizens. With the transfer of power from the occupation policy, measures taken by these sanatoria authorities against the self-governing associations also added a political aspect: the national government was to support these measures. The 1953 Leprosy Prevention Law was different from the old law prior to the war in terms of such characters that it was not used as the ground for the implementation of expanding the size of sanatoria; rather, it was to suppress opposition movements against the "all-patients" confinement policy and to maintain the system of "national" sanatoria regime.

#### B. Role of Public Health Centers in the Post-War "All-Patients" Confinement

GHQ/SCAP made a recommendation to the Japanese government to re-establish public health centers. In response, the Public Health Center Law (Law 42, April 5, 1937) was completely revised on Sept. 5, 1947, and the revision went into effect in January 1948. Under this new law, 675 public health centers were in existence all across the country, with 18,857 staff members, which was about three times as many compared to the pre-war figure. In the city of Fukuoka, the city-funded Fukuoka Public Health Center was founded in January 1949. According to the job assignments at Fukuoka Public Health Center, The Prevention Section under the Public Health and Prevention Division was in charge of Hansen's disease.

Unlike in the pre-war situation, the post-war "Leprosy-Free Prefecture" campaigns differed significantly from prefecture to prefecture. The main reason for this change seems to be the fact that the authorities that were most directly involved in the compulsory segregation policy changed from the centralized public-health police to municipally operated public health centers. However, this does not mean that the post-war "Leprosy-Free Prefecture Campaigns" were smaller in size or power than the pre-war campaigns. Instead, because the public health centers were directly involved, the base of the campaign was extensively expanded so as to include doctors and nurses, and the "good faith" of these people involved turned out to be more powerful in forcing "all-patients" confinement than the public-health police "authority."

#### C. GHQ's Handling of the Hansen's Disease Problem

To analyze the response of GHQ concerning Japan's policy on Hansen's disease, it is reasonable to consider the first and second halves of the occupation separately. During the first half of the occupation, GHQ was not very interested in Hansen's disease as already described in detail in the section "Hansen's Disease Policy for Japan by GHQ" above. They simply continued with the segregation policy -which was practiced since before the war- of patients into "national sanatoria". The only exception was Okinawa and Amami, the territories under the United States' military government, where the United States forces not only continued the segregation policy of Japan but also treated Hansen's disease patients as part of their colony control. Even after the San Francisco Peace Treaty came into effect, the United States' government controlled Amami until 1953 and Okinawa until 1972. The mode of their governing changed from military government to civilian government, but the situation was not changed.

## **D.** Relationship between "Release Due to Improvement" and the "All-Patients" Confinement Policy

In November 1947, shortly after the war, Higashi, director of the Medical Bureau, announced in the Health and Welfare Committee of the House of Representatives that the government policy will be one of "all-patients" confinement, and at the same time that improved patients would be released from the sanatoria. This attracts special attention as a new direction different from the pre-war policy; however, the announcement did not mean that the post-war "new bureaucrats" in the Ministry of Health and Welfare even considered banning the compulsory segregation policy. To them, allowing the release of improved patients was not in contradiction with "all-patients" confinement at all. In fact, the opposite is true. In order to promote "all-patients" confinement by using an extremely loose interpretation of "patients that may be contagious," it was necessary to make room by allowing improved patients to be released. In this sense, the concept of release due to improvement was just a theoretical idea; in actuality, it was a "door that could never be opened."

#### E. Relationship between the Security Policy and the Policy on Hansen's Disease

During the last half of the occupation, i.e. between 1949 and April 1952, when the peace treaty came into effect, the occupation policy went through a transition. The "de-militarizing" and "democratizing" policies in the first half of the occupation were limited and phased out by the emergence of a new system of "control laws" In regard to the law on security, a new security law would replace the pre-war "Imperial System Security Law." In June 1950, the Korean War began. In July, Gen. McArthur ordered the establishment of the National Police Reserve. In an effort to make Japan a buffer zone against communism, orders were given to remove from public office 24 central committee members of the Japan Communist Party in June of the same year, and in July the party's newspaper Akahata (The Red Flag) was ordered to stop its publication indefinitely. These movements had a tremendous impact on Hansen's disease policy. For example, the patient self-governing association paper at Kuryu Rakusen En stated the following concerning the Heavy-Security Cell problem: "The Ministry of Health and Welfare bureau was exactly marked by its frantic effort to adamantly make patients' struggle out to be a puppet backed up by the Communist Party." The House of Representatives decided to send an investigation team from the Health and Welfare Committee, but no members of the Communist Party were selected for this team. The policy against self-governing association movements was painted with a very political color called an anti-Communist policy. The national sanatoria were, therefore, really "national" sanatoria in a political sense also. The voice of Mitsuda, etc. for suppressing self-governing association movements is exactly what the government ended up supporting.

In light of such a relationship between the government's security policy and the

Hansen's disease policy, the following statement by Yoshio Morita, a staff member of the Immigration Service, makes sense: "In 1951 Nagashima Aisei En made an inquiry to various agencies concerning criminal leprosy patients. As a result, it was discovered that there were 44 criminal leprosy patients (the Osaka district's reply did not arrive); 17 of them were Koreans. In the branch medical prison at Kikuchi in Kumamoto prefecture, there were 17 leprosy patients, 13 of whom were Koreans (as of Sept., 1951)" (source: "Justice Research Report," *Estimates and Realities of Treatment of Koreans in Japan*, Vol. 43, Issue 3, July, 1955). One can see that the focus in the treatment of Hansen's disease patients was crime prevention, particularly of Korean citizens in Japan. Hence, under the Korean War and the Cold War structure, GHQ did not support the self-governing association movements, which asked for a ban of the compulsory segregation policy, but rather sided themselves with the opposing side; this is not too difficult to understand.

## 8. "Leprosy Prison"-1953 "Leprosy Prevention Law" #4 (\_2\_6)

#### A. Elimination of Heavy-Security Cells

In 1947, the "Special Wards," i.e., heavy-security cells, at Kuryu Rakusen En were eliminated. This caused some sanatorium directors to express their needs for another facility that would replace the Heavy-Security Cells. The elimination of heavy-security cells had a huge impact on the nation regarding the treatment of Hansen's disease patients who broke a law. In other words, until that time, if a Hansen's disease patient broke the law, since the patient was, because of the segregation policy, not allowed to be placed in a normal jail or detention center, the government could virtually leave them to stay within the sanatorium-in confinement or, if the criminal is a felon, in a Heavy-Security Cell. The elimination of Heavy-Security Cells led to the loss of such places. Furthermore, under the new Constitution of Japan, confining patients without any judicial decision, i.e., disciplinary restriction and detention rules itself under the (Former) Leprosy Prevention Law, was questioned as being unconstitutional. Thus a need for prisons exclusively for Hansen's disease patients, i.e., "leprosy prisons," was into reality.

#### **B.** Opening of "Leprosy Prisons"

As the Ministry of Justice and the Ministry of Health and Welfare began discussing this "leprosy prison" idea, GHQ communicated its view through the Ministry of Justice to the Ministry of Health and Welfare on August 4, 1949. The view was the following: "Leprosy patients are not to be subject to criminal punishment, even if they are guilty of crime; instead, they should be subject to treatment and protection. They should thus be placed in facilities operated under the Ministry of Health and Welfare and be given appropriate protection."

On the other hand, the Ministry of Health and Welfare stressed the fact that police did not get involved in crimes committed by Hansen's disease patients and emphasized that, while more serious patients could be exempt, less severe patients was necessary to be punished for their criminal acts. Hence, the gap widened between the Ministry of Health and Welfare-who continued to ask for "leprosy prisons"- and the Ministry of Justice, who wanted the criminal patients to stay in sanatoria. On August 24, the Ministries of Health and Welfare and Justice met together for cooperation. There, the Ministry of Justice presented a compromise proposal that had the following items: in each national sanatorium for Hansen's disease, a detention center and special rooms for investigation and judgment will be established, setting aside a part of the sanatorium as a "substitute jail"; and to this end, the law would be revised to appoint some of the sanatorium staff as special law-enforcement police officers. In response, the Ministry of Health and Welfare agreed, saying, "There are no other options" (source: "Process Leading to a Request for Budget Estimate to Establish Specially Monitored Medical Buildings (Which Function as Substitute Jails or Detention Centers) in National Leprosy Sanatoria," Medical Bureau of the Ministry of Health and Welfare).

In October of the same year, there was a hospital-management conference held in Tokyo, where national hospital directors and national sanatorium directors had gathered together. Taking advantage of this opportunity, a meeting of the directors of national leprosy sanatoria was held there; it was decided (with a vote of 7 to 3) that a "leprosy prison" would be established in Kikuchi Keifu En (source: Matsunori Miyazaki, "How the Leprosy Prison Was Born," *Kyushu Khosei* Vol. 8, Issue 5, May, 1953).

In the midst of this discussion of the "leprosy prison" concept, sometime between late night of January 16, 1950, and the dawn of January 17, three residents of Kuryu Rakusen En were murdered due to conflicts among residents. Complicating the issue was the fact that one of the victims was a Korean citizen and the 14 residents that had allegedly taken part in the murder were also members of Kyoshin Kai, the cultural organization of Korean residents. This case had two major impacts on the Hansen's disease policy. First, the need to establish "leprosy prisons" was more emphatically voiced than before. Second, the need to control Korean patients was also more emphatically voiced than before.

Only a few days after the murder, on January 31, Katsuji Hisashita, Deputy Director of the Medical Bureau of the Ministry of Health and Welfare, stated the following in a Health and Welfare Committee meeting of the Seventh session of the House of Representatives: "If one is convicted of a crime and is sentenced to punishment through due process of the law, even if he or she is a leprosy patient, the guilty person should be put in a normal prison." He then adds that, to this end, it is thus appropriate to "build a prison for leprosy patients at site where communication with a leprosy sanatorium is possible" (source: "Proceedings of the Health and Welfare Committee, House of Representatives of the 7<sup>th</sup> Diet," No. 3).

The Health and Welfare Committee of the House of Representatives visited, between March 7 and 10, Rakusen En, Nakanojo Branch of the Maebashi District Prosecutor's Office, Gunma Azuma District Police Department of the National Local Police, and Kusatsu-cho Police Department for on-site investigation. Naotomo Maruyama, an investigator, stated in the same committee, "judicial power must be invoked to leprosy patients exactly in the same way as to anyone else." He also added, "One or two special prisons must be established adjacent to leprosy sanatoria" (source: "Proceedings of the Health and Welfare Committee, House of Representatives of the 7<sup>th</sup> Diet," No. 14).

On July 5, The director of the Public Health Bureau of the Tokyo Metropolitan district sent an inquiry "Concerning the Treatment of Criminal Leprosy Patients" to the director of the Medical Bureau of the Ministry of Health and Welfare, asking for

instructions by describing the reality and state of confusion concerning the treatment of "leprosy patients found in police detention centers" and "leprosy patients found in jails."

In response, Ryutaro Higashi, the director of the Medical Bureau, wrote to the Chief Detective of the National Local Police Headquarters on July 18 concerning "Treatment of Criminal Leprosy patients." He requested that if a criminal in a detention center was diagnosed with Hansen's disease, the patient was to be disinfected and to stay at the detention center; when he was indicted, he was to be sent to a jail. He also requested that one or more "leprosy detention centers" be established for each prefecture. He then sent the same document to the director of the prosecutor's office in the Justice Agency as well as the director of the Correction and Protection Bureau. He requested that until "permanent facilities have been built for criminal leprosy patients' confinement," such criminal patients be treated as normal criminals and stay in the imprisonment after being disinfected at the prison or jail.

The Chief Detective of the National Local Police Headquarters responded to the director of the Medical Bureau of the Ministry of Health and Welfare on July 31. There, he recognized that, while he had requested that money be allocated in the FY1951 budget to "build two new special detention rooms for temporarily holding suspects with leprosy or other infectious diseases in those prefectures where sanatoria are located," the current practice and policy was to send to sanatoria those who were diagnosed with Hansen's disease in detention centers.

The response of the prosecutor's office of the Justice Agency came from the staff of the director on October 7: "Concerning the Treatment of Criminal Leprosy Patients." The writing is vague, stating that the treatment of Hansen's disease patients in detention centers and jails who may be contagious," should be determined by the appropriate police chief or jail director in consultation with the prosecutor in charge."

As seen here, the Ministry of Health and Welfare and the Justice Agency did not show agreement on the concept of "leprosy prisons." In the midst of this, on July 15, a robbery occurred in Kumamoto prefecture, in which some police officers were stabbed. And one of the suspects arrested was released without indictment because he was a Hansen's disease patient. The prosecutor's office asked Kikuchi Keifu En to admit this suspect. Kikuchi Keifu En, unable to refuse this request, admitted the man, but this incident led to a conference on July 18 of the Kumamoto District Prosecutor's Agency, Kumamoto Prison, and Kumamoto Prefecture Public Health Department. The parties agreed that "neither the Prosecutor's Agency nor the prison find no reason to exempt a suspect from legal penalties just because he has leprosy"; and that "an urgent request should be made to establish leprosy prisons" (source: Matsunori Miyazaki, addressed to the Minister of Health and Welfare, "A Report on the Robbery and Attempted Murder by Stabbing of Police Officers by a Leprosy Patient, 1950).

As seen here, the need for "leprosy prisons" had become a serious and real problem. The Ministry of Health and Welfare and the Justice Agency then agreed to establish a "leprosy prison" on the premises of Kikuch Keifu En; the FY1951 budget included appropriation for this, and on January 19, 1951, the Ministry of Health and Welfare and the Justice Agency came to an "agreement concerning the operation of correction and protection facilities for convicted leprosy patients"; it included such points as "if the prison has a difficult time finding facility staff to employ, the Ministry of Health and Welfare shall provide the needed number of workers" and "the medical staff of Kikuchi Keifu En shall also attend to the medical needs of the leprosy prison" (source: Matsunori Miyazaki, "How the Leprosy Prison Was Born," previously cited).

On March 10, 1953, the "leprosy prison" was opened as the medical branch of Kikuchi Prison. The capacity at the opening was 75. The operation policies were as follows: "While those placed here are equally guilty of crime, they are nevertheless sick. They are criminals to whom we should have compassion because their future is extremely gloomy. Hence, unless they violate the rules of the facility, their motivation for rehabilitation should be encouraged by our showing overwhelming love and mercy; since they are sick, as far as treatment is concerned, they are to be dedicated to receiving treatment exactly in the same way as at a leprosy sanatorium; and those in less severe state who can endure labor should be put to appropriate work in the facility such as plowing land and growing flowers" (Kikuchi Medical Prison Branch Overview).

# 9. Truth about Fujimoto's Case-1953 "Leprosy Prevention Law" (\_3)

# A. What Is Fujimoto's Case?

Fujimoto's Case refers to the two incidents (the dynamite incident and the murder incident) that occurred at Suigen Village in Kikuchi County (currently Kikuchi-shi), Kumamoto Prefecture, in 1951. These events occurred against the backdrop of the compulsory segregation policy accompanying the post-war "Leprosy-Free Prefecture Campaign," the expansion plan of Kikuchi Keifu En, and the establishment of Kikuchi Medical Prison.

The implementation plan of the Leprosy-Free Prefecture Campaign, passed in June 1949, included the expansion of capacities at sanatoria and thorough confinement of all patients not yet placed in sanatoria by roundup medical examination of patients. Along with this, the expansion plan of Keifu En was carried out, and by June 1951, it had become the largest sanatorium, with a capacity of 2100 patients. In order to fill this sanatorium, the prefecture needed to secure more patients. Parallel to the expansion plan, in April 1950, under the "all-patients" confinement policy of the government, under which all Hansen's disease patients were to be placed in sanatoria, the prefecture began compulsory confinement of "leprosy" patients. Matsuo Fujimoto, the defendant in the Fujimoto's Case, was one of the patients told to go to a sanatorium by the prefecture at this time. In August 1951, an "attempted murder incident" by dynamite occurred at a family's private residence where one of village office staffs lived, who was involved in his confinement suasion. Fujimoto was arrested as the suspect.

The way in which this incident was viewed by the surrounding public was revealed clearly in the following remark. Immediately after the dynamite incident, on November 8, 1951, Matsunori Miyazaki, the director of Keifu En, made the following remark in the so-called "three-director speech" at a meeting of the "Leprosy Subcommittee" in the Health and Welfare Committee of the Upper House: "The patient who was notified about confinement claimed that his leprosy was made known only because the head of Public Health reported it to the prefecture. He bore a grudge then and was determined to kill the entire family..." The trial had not begun at this stage, so the suspect was not found guilty yet when this director stressed the link between the incident and the confinement suasion in this comment about the case. Matsuo Fujimoto later escaped from the prison within Keifu En, but during the escape that village office staff was killed. This murder case was also linked to him, as if it was the natural course of events, under the assumption of "the leper's grudge."

At this time, while Keifu En was expanding according to the plan, building of a prison exclusive for Hansen's disease patients was also planned. Despite opposition by the self-governing association, in March 1953, the Kikuchi Medical Prison Branch was completed right next to the property of Keifu En, with a capacity of 75. Matsuo

Fujimoto was placed in this "leprosy prison," but he continued to claim his innocence. However, after this, without ever being tried in the regular court, he was sentenced to death in August of the same year. This is the same month in which the (New) "Leprosy Prevention Law" was passed. While appeals and requests for retrials continued, he was executed in Fukuoka Prison in September 1962.

### **B.** Problems in the Case

#### 1. Establishment of Special Courts

In accordance with Section 2, Article 69, of the Court Law, this case was tried in the special court using the facility of Kikuchi Keifu En in a mode called an "extension court." Once the defendant was diagnosed with "leprosy," there was no hesitation with this procedure. Justice irresponsibly allowed the public court trial to take place at this location without any trouble.

The fact that a public trial took place inside Keifu En, as a special court, meant, of course, that the general public was extremely difficult to hear the case as observers. In other words, this trial was carried out virtually "closed to the public."

### 2. Problems with the Trial Procedure

The effect of the fact that the defendant was a patient of Hansen's disease can be seen throughout the entire procedure, from investigation, forensics, public trial procedures, to the execution.

Matsuo Fujimoto was shot by a gun while being re-arrested during his escape. He went through interrogation while in pain. It appears that even during this interrogation, he was basically requested to make a confession while the investigators hardly heard anything that the defendant had said due to their fear of Hansen's disease. Even in the forensic stage, the clothes of the defendant, used as evidence, went to the forensics after they were disinfected; the professor who examined them stated in writing, to result in sloppy forensic examination, very unscientifically, "The sample for investigation is dirty," and "affected by somehow unknown physical and scientific, or bacterial or the like, infestation." The trial was orchestrated to appear as if it was a "normal trial." However, the trial was really taking place in very odd circumstances, wherein everyone except the defendant had white lab coats and long rain boots. The judge also seemed to be extremely scared of Hansen's disease; he did not allow the defendant to directly touch any evidence exhibits by hand.

Therefore, starting from the setting of the special court, it is totally undeniable that discrimination and prejudice constituted a large factor in this trial, even through the public trial procedure.

#### 3. Problems with Fact Verification (Witnesses' Testimonies)

The fact that the defendant's attorney had agreed to examine all the evidence<sup>§</sup> certainly made it difficult for the defendant to maintain the right to defend himself. However, there was something even more problematic. The deciding evidence for the guilty judgment was the testimony of two witnesses. This had been admitted as evidence, i.e., "prior evidence" before the suspect was arrested and thus before his defense was even heard. If these two witnesses changed their testimony in the public trial, they could be guilty of perjury themselves; hence, it is quite possible that protective consideration for them was an influencing factor in getting the defendant's confession.

#### **C. Death Penalty**

In the first instance, the sentence was given on August 29, 1953; it stressed the grudge held against the victim. The decision stated that the defendant committed the murder even though "he was diagnosed as a leprosy patient based on an authoritatively scientific diagnosis and therefore should have submitted to this reality, giving himself to appropriate medical care by physicians, enduring the mental and physical pains during the treatment, hoping that one day he would happily recover to full health, and dedicating himself strictly and only to such treatment; this was his only way of life." Without considering any contradiction found in the forensic process or contradictions in the so-called "confession" of the defendant, the defendant was sentenced to death.

#### **D.** Appeals and Campaign for a Fair Trial

After his death sentence in the first instance, the defendant immediately made an appeal to the High Court of Fukuoka. With the support of the All-Japan National Leprosaria Patients' Association, Masaji Nojiri (of the Bar Association of Kumamoto Prefecture) became his attorney. Later, in the Supreme Court, Mutsuo Shibata and Yu Sekihara joined Nojiri on the defense team. For the first time, they pointed out the problems with the special court, prejudice and discrimination against Hansen's disease patients, and asked for sufficient consideration. The Supreme Court, however, dismissed the appeal on August 23, 1957, stating that, "there is no evidence that the trial decision in the lower court was made with preconceived prejudice and discrimination, against conscience."

The "Campaign for a Fair Trial" in Fujimoto's Case had begun in the middle of opposition movement against the 1953 revision of the "Leprosy Prevention Law." With the support of not only the patients in sanatoria but also a large number of people living

<sup>&</sup>lt;sup>§</sup> (Note by translator) This means the waiver of the right of defendant to cross examine every hearsay evidence.

outside, the campaign developed into the "Group to Rescue Mr. Matsuo Fujimoto" by 1958. Their view was that the real essence of Fujimoto's case was the social prejudice against Hansen's disease patients and improper government policy on Hansen's disease. While requests for a retrial were submitted, supporters of the campaign carried out an on-site investigation in 1962. While second and third on-site investigations were planned, the third request for a retrial was rejected. The death sentence was carried out on the very next day, September 14. The execution was done almost as though they already knew that the request for a retrial would be rejected; there is no doubt that such an execution built a "thick wall" around the rights of a defendant who claimed innocence. Across the country, large-scale demonstrations took place, one after another, as people heard of the execution. They showed the shock that the society felt against the fact that this ultimate sentence was carried out with preconceived prejudice and without exhausting sufficient procedural measures.

Ironically, with two more weeks after the execution, Matsuo Fujimoto would have been in the "Leprosy Prison" for ten years after being sentenced with 10-year imprisonment for the dynamite incident. But the system at that time had no facility for "patients" who were on death row, having lost the position and status of a convicted prisoner. Even the "Leprosy Prison," created to "isolate" Hansen's disease patients from the justice system based on discrimination and prejudice at that time, was not really a place where he could stay. The suspiciously sudden execution of Matsuo Fujimoto can be interpreted as a contradiction in a justice system born out of such discrimination and prejudice.

# **E.** Conclusion

At a glance, the investigation and trial processes of this case appear to have been carried out in a legal manner; however, from a constitutional viewpoint, the case has many contradictions.

The Constitution guarantees the right of access to courts and the right to speedy and public trial by an impartial tribunal based on due process. Hence, the defendant is guaranteed the right to an attorney, the right to remain silent, and the right to cross-examination. Furthermore, the defendant has the right not to testify against himself and cannot be forced to do so, and no person shall be convicted or punished in cases where the only proof against the defendant is the defendant's confession. It goes without saying that these are minimum requirements for a government to apply its punitive authority in penalizing a person, who is otherwise entitled to his freedom. In other words, all the criminal procedures established in the Constitution are to ensure that the suspect/defendant's human rights be sufficiently protected and that investigations and trials be carried out under such full and complete procedural protection. Only when such procedural protection is sufficient, is the judge authorized to find facts according to his own evaluation. Fujimoto's case did not even come close to satisfying the constitutional requirements.

# 10. Role of the Toufu Association and the Imperial Family-1953 ''Leprosy Prevention Law'' #4(\_4)

# A. Empress Teimei and the Hansen's Disease Problem

Empress Teimei "provided" an "imperial allowance" to help establish the Leprosy Prevention Association and composed a poem called "Comforting Leprosy Patients." She became known as a symbol of "leprosy salvation." In turn, Hansen's disease patients were ideally symbolized as recipients of "compassion" by the imperial family.

#### **B.** Imperial Ceremonies and Hansen's Disease Patients

Two modern-day "major ceremonies," i.e., emperor coronation ceremonies, were the "Taisho Coronation" in November 1915, and the "Showa Coronation" in November, 1928. Segregation of Hansen's disease patients were reinforced on both of these occasions. To isolate and accommodate homeless patients around Kyoto, Hokajima Rest Center in Osaka was expanded each time. These "major ceremonies" were difficult times for Hansen's disease patients.

### C. Establishment of the Toufu Association

On May 17, 1951, when Empress Teimei passed away, some political and business figures expressed their desire to see her inheritance go toward "leprosy salvation" to commemorate her "compassion" towards Hansen's disease patients. As a result, donations were sought widely among people, and in June 1952, the Foundation Toufu Association was established with Prince Takamatsunomiya Nobuhito as president. Hiroshi Shimomura became the chairman of the board, and the business of the Leprosy Prevention Association up to that time was succeeded by the Toufu Association.

This was at a time when the All-Japan National Leprosaria Patients' Association was involved in the Battle over the revision of the Leprosy Prevention Law. Almost as if to silence this force, imperial "compassion" was emphasized, and patients were asked to stay as objects of such mercy and pity. Furthermore, from its very birth, the Toufu Association was connected to the Ministry of Health and Welfare. By stressing imperial "compassion," they were promoting the public opinion that would support government policy, consisting of repressing the movement of the All-Japan National Leprosaria Patients' Association, eliminating altogether patients with Hansen's disease, who were against the "civilized country" concept, and reinforcing the segregation policy.

# 11. Reasons for the Delay of Repeal of the "Leprosy Prevention Law" of 1953 #51

### A. Question

The Leprosy Prevention Law of 1953 was from the beginning a law without legislative facts (a factual reason for its existence). Despite this fact, backed up by the power of the Ministry of Health and Welfare and the chief doctors of national sanatoria, the stipulations of this law forcefully maintained and even enhanced the stipulations of the 1907 law and the 1931 law as well as the existing conditions of the national sanatoria, etc.

Why then was this law, which did not have a factual basis for existence in the first place, not repealed until 1996? The most fundamental factor is two-fold. One is that the government administration of medical and welfare affairs, making light of the fundamental problem of discrimination and prejudice, concluded that the status quo (the current law) was advantageous as policy for improvement in treating patients and residents of the sanatoria (the "double-sided view" of compulsory segregation and treatment improvement), only seeing the problem from a pragmatic viewpoint. The other is that the sanatorium-centered policy had given vested interests to the Ministry of Health and Welfare and the Japan Leprosy Association.

Here, we focus on legislature, executive administration, and the Japan Leprosy Association, taking into consideration the current of self-governing association movements and the All-Japan National Leprosaria Patients' Association movements, in order to find the reasons and grounds for the much-delayed repeal of the 1953 Leprosy Prevention Law.

#### **B.** Actions of the Legislative Branch

Legislative power officially belongs to the Diet, but it is often said that Japan's laws have been predominately written by the executive branch. Placement of a patient in a sanatorium provided for by Article 6 of the 1953 Leprosy Prevention Law did not have medical or scientific grounds. The legislature, having listened to the speeches of three national sanatorium directors in 1951, hardly even bothered to discuss the medical and clinical issue concerning the fact that generally Hansen's disease is very unlikely to be transmitted to reach the onset of the disease. They simply added a resolution that is not legally binding. This added resolution implicitly allowed an excuse made by the executive branch that for the administration (staff in the executive branch) to interfere with the problem of law revision, which rightly belongs to the Diet, was an infringement of the balance of power.

#### C. Actions of the Executive Branch

There was some movement toward the revision of the law within the Ministry of Health and Welfare, maybe in reaction to the large-scale movement in 1963 by the All-Japan National Leprosaria Patients' Association calling for a revision. However, it was not enough at that time to achieve any revision.

The reason that the Ministry of Health and Welfare generally did not seriously or directly get involved in revision of the 1953 law and that revision was delayed for such a long time appears to be as follows. In order to obtain the budget necessary for improving the treatment of residents in sanatoria, the Ministry of Health and Welfare emphasized, to the Ministry of Finance, the existence of the segregation requirement under the New Law, taking maximum advantage of the requirement; in other words, it was the double-sided theory of compulsory segregation and treatment improvement. The Ministry of Health and Welfare was "emphasizing the existence of the segregation requirement under the New Law to the Ministry of Finance in order to obtain the budget necessary for treatment improvement, taking maximum advantage of the requirement." This double-sided theory was dominant in the Ministry of Health and Welfare and is considered the fundamental reason for delay in the repeal of the 1953 law.

It appears that the Ministry of Health and Welfare was of the opinion that the law, being a national-scale problem, should be revised after a certain level of accomplishment had been achieved (patients returning to society, etc.) and that it was safer to change the system little by little along with substantial development. However, this type of opinion had already missed an opportunity and been overdue at the time. In this sense, such an opinion was a fictional theory that existed only on paper. Returning to society was at its peak in 1960; since then, the number has become smaller.

In 1949 the director of the Social Bureau of the Ministry of Health and Welfare responded that the right to request protection under the Living Protection Law would not be legally acknowledged. The Constitution of Japan did guarantee individual's rights to life and pursuit of happiness, but citizens were not subjects with these rights; rather, they were just objects of protection. The same is true with medical care. It became possible to limit medical care only to inside sanatoria, thus strengthening the policy of all-patients confinement. The Program Theory concerning Article 25 of the Constitution, denying the specificity of the right of life, became a standard interpretation in scholarly circles, establishing itself as a judicial precedent as well. In the first instance of the so-called Asahi Lawsuit at Tokyo District Court in 1960, an innovative decision was made to fully accept the claims of Shigeru Asahi; however, the Supreme Court dismissed an appeal made by Shigeru Asahi in 1967. This Supreme Court decision made the double-sided theory of compulsory segregation and treatment improvement emerge.

The Law to Repeal the (New) Leprosy Prevention Law stipulated that sanatoria be

maintained after the law is abolished and guaranteed living protection of the residents and their families. However, this is considered a result of the economic struggle fueled by self-governing association campaigns and All-Japan National Leprosaria Patients' Association campaigns.

# **D.** Actions of the Japan Leprosy Association and the Ministry of Health and Welfare

Since Dr. Noboru Ogasawara was viciously attacked in 1941 at the Japan Leprosy Association, the physicians of the national sanatoria maintained the authority and political power to influence the trend of the Association. As a result, opportunities where knowledge, information, and opinions of relevant international associations could be used as basis for judging, from a relative perspective, medical and scientific knowledge and opinions closely linked to the policy for Hansen's disease in Japan, were severely limited.

Meanwhile, communication between the Ministry of Health and Welfare and leprosy associations-both domestic and foreign-did not occur as a system but was rather carried out by individual efforts of staff members of the Ministry. Despite their efforts, under the circumstances it was impossible to carry out the government administration of medical and welfare affairs based on medical and scientific evidence. Instead, the administration resulted in unclitically following the opinion of specific doctors.

The Japan Leprosy Association was managed by the doctors of the national sanatoria and was closely connected to the Ministry of Health and Welfare. The policy -centered on national sanatoria- gave a variety of vested interests-both in terms of human resources and budget finance-to the Ministry of Health and Welfare and the Japan Leprosy Association. This appears to be the very force of habit that automatically affirmed the status quo.

# E. Patients and Residents as Objects of the Medical and Welfare Policies

Around 1962 and 1963, patients were treated only as objects of medical and welfare policies and never as subjects that could speak or express themselves. Hence, requests for revision by the All-Japan National Leprosaria Patients' Association in 1963 and 1991 could not be reflected in the policy.

# F. Circumstances on the side of the All-Japan National Leprosaria Patients' Association and Self-Governing Associations

After the enactment of the 1953 Leprosy Prevention Law, the All-Japan National Leprosaria Patients' Association came to shift to economic struggle. At this stage,

however, this battle was not in contradiction to the Battle against the Prevention Law which had begun in 1951; instead, it was one of the two pillars of the All-Japan National Leprosaria Patients' Association movement, the other pillar being a request for revision of the Prevention Law.

Among patients, who were cured by powerful medicine such as Promin, some of those came out to return to the society, but the "thick wall" in the society began causing the number of returnees to go down in 1960. Beginning around that year, the All-Japan National Leprosaria Patients' Association and self-governing associations began switching their focus from "return to society" to treatment improvement for the patient-residents. The Ministry of Health and Welfare also worked seriously to improve treatment, and the Ministry maximized in the negotiation with the Ministry of Finance the use of the double-sided theory of compulsory segregation and treatment improvement.

After 1975, when treatment improvement, although just reaching a certain level of the treatment, at the sanatoria was realized, the economic struggle of the All-Japan National Leprosaria Patients' Association and self-governing associations began to change its character. The struggle got stuck into the "either-or" choice: itself or the Prevention-Law repeal or revision movement. Under such circumstances, some suggested that the associations stand up once again to fight the Battle against the Prevention Law, but many of the self-governing associations did not actually support this proposal. This is because they thought that repealing the Prevention Law would contradict the maintenance of the existing standard of treatment and the request to improve it.

Hence, given the circumstances at that time, in order to fight the Battle against the Prevention Law again, it became urgent to defeat the "double-sided theory of compulsory segregation and treatment" from the standpoints of the constitutional theory and the theory of human rights as a theoretical action to distinguish between obtaining human rights and guaranteeing treatment. However, legal experts did not take this responsibility, and this task was delayed for more than 20 years. In addition, the revisited Battle against the Prevention Law needed the support of a wide variety of people in society, and the mass media was to play a major role in this. However, during this period, based on the presupposition (backed up by an apparent fact) that a certain level of treatment improvement had been achieved, the interest of mass media in Hansen's disease became slim. Thus, the lack of responsibility by legal experts and the lack of understanding by society made residents in sanatoria give up their hope for return to society and made the "double-sided theory of compulsory segregation and treatment improvement" the dominant thinking. And, after a certain level of treatment improvement was achieved, this also made residents in sanatoria become very careful, in order for treatment to be guaranteed, about asking for revision or repeal of the Prevention Law.

# G. Proposal for a Revision of the "(New) Leprosy Prevention Law" by the Federation of Directors of National Sanatoria in 1976

After 1975, the All-Japan National Leprosaria Patients' Association and self-governing associations always put off the issue of revising the Prevention Law by stating that, "this requires further careful discussion." Apparently it was considered that the chances were that this issue would divide each organization considerably, causing them to fear organizational splits.

On the government side, there was no special reason to have to accept the proposal of the directors' federation, either. In fact, speaking of a revision to the Prevention Law could contradict what they had been saying to the Ministry of Finance all along. It is doubtful that even the directors of the sanatoria, although they had submitted the proposal, was very serious about the proposal being accepted.

# **H. Recommendation**

A request should be made to the Ministry of Finance that the following new principle be followed in preparing a budget: In prevention, examination, screening, treatment, rehabilitation, hospital stays and/or visits, and other situations relating to medical practice with infectious diseases and mental or psychiatric practice, the traditional policy seen so far has been that no funds would be appropriated unless there is a legal factor of mandatory obligation; however, it must be realized that such a policy has collapsed in the light of the dignity of human beings and respect for human rights; hence, efforts should be made to adopt a new policy wherein funds may be appropriated without a legal factor of mandatory obligation so long as there is a reason to do so for the purpose of public health.

# 12. Clarification of the Reality of the Creating and Fomenting of Prejudice and Discrimination against Hansen's Disease #6

# A. Pre-War Leprosy-Free Prefecture Campaigns

### 1. Establishment of a "Leprosy Prevention Day"

The term "Leprosy-Free Prefecture" literally means a prefecture without Hansen's disease patients, where all patients have been segregated and all homeless patients and patients staying at home have been eliminated. This term was first used in Aichi prefecture in 1929 but spread widely after the implementation of the absolute segregation policy in line with the issuing of the 1931 "Leprosy Prevention Law." The concept was even further stressed after 1936, when the "20-year extermination plan" of all Hansen's disease patients began. A "Leprosy-Free Prefecture Campaign" was a movement wherein the public and private sectors jointly made efforts to detect every patient and to send each one to a sanatorium in order to realize a "Leprosy-Free Prefecture." Such campaigns were supported by the Leprosy Prevention Association, Japan MTL, and religiously affiliated organizations, such as Ohtani-ha Komyokai.

#### 2. Building of Thirty-Three-Square-Meter Residences

As these "Leprosy-Free Prefecture Campaigns" became active, the number of isolated patients also increased, causing sanatoria to go beyond their capacities. At Nagashima Aisho En, which had always been with a problem of excess patients since its opening, Kensuke Mitsuda, the director of the sanatoria, came up with the idea of starting a campaign to build 33-square-meter residences as a solution to the problem. The idea was to ask for donations from people across the country, use the labor of patients at the sanatorium to build 33-square-meter residences with two rooms of 6 tatami mats each, and donate these buildings as government assets. This way, the extra patients could live in these residences ("10-Tsubo Residences," ed. by the Solidarity Group of Nagashima Aisei En, 3<sup>rd</sup> ed., 1936). There were altogether 82 of these residences built between 1932 and 1937 ("10-Tsubo Residences," ed. by the Solidarity Group of Nagashima Aisei En, 6<sup>th</sup> ed., 1937).

# 3. Progress in "Leprosy-Free Prefecture Campaigns"

Under the "Leprosy-Free Prefecture Campaign," more national sanatoria for Hansen's disease were built. The first national sanatorium was Nagashima Aisei En, built in 1931, followed by Kuryu Rakusen En in Gunma prefecture in 1932, Hoshizuka Keiai En in Kagoshima prefecture in 1935, and Tohoku Shinsei En in Miyagi prefecture in 1939. In addition to this, in 1931, Miyako Therapy Center was built by Okinawa prefecture on Miyako Island. In 1933, this center became Temporary National Miyako Sanatorium.

As these national sanatoria were being built, it became apparent that the goal of isolating 10,000 patients under the "Twenty-Year Extermination Plan" (begun in 1936) would be possible to achieve by 1940, thanks to a donation given by Mitsui Ho-on Foundation in November 1936. The year 1940 would be the "2600<sup>th</sup> year of the Imperial Dynasty." The "Leprosy-Free Prefecture Campaign" was linked with this "Celebration" of the "2600<sup>th</sup> year of the Dynasty"; its importance was advertised, and as planned, that year saw the goal of the segregation of 10,000 patients achieved.

As the "Leprosy-Free Prefecture Campaign" continued to advance, it became necessary for public sanatoria to become nationally funded sanatoria since the public sanatoria had regional characteristics, Sections 1 through 5, whereas national sanatoria has no geographical characteristics concerning their patients. For example, if a patient was registered in Tokyo, the patient in general was to be isolated in Zensei Hospital, in Section 1. Hence, there was incoherence that even if a public sanatorium has more room, it could not make patients placed there from outside its territory. On July 1, 1941, all public sanatoria were transferred to as national sanatoria. Kunigami Airaku En of Okinawa prefecture also transferred to became a national sanatorium, and the Temporary National Miyako Sanatorium too became National Miyako Nansei En. With these changes, the number of national sanatoria for Hansen's disease became eleven: in addition to the already existing ones, Nagashima Aisei En, Kuryu Rakusen En, Hoshizuka Keiai En, and Tohoku Shinsei En. The additional ones were Matsuoka Therapy Center (formerly Hokubu Therapy Center), Tama Zensho En (formerly Zensei Hospital), Oku Komyo En (formerly Komyo En), Oshima Seisho En (formerly Oshima Sanatorium), Kikuchi Keifu En (formerly Kyushu Sanatorium), Miyako Nansei En, and Kunigami Airaku En.

# **B.** Post-War Leprosy-Free Prefecture Campaign

1. Continuation and Expansion of the "Leprosy-Free Prefecture Campaigns"

In 1947, Matsunori Miyazaki, the director of Kikuchi Keifu En, stressed the continuation of the "Leprosy-Free Prefecture Campaign"; on November 7, the director of the Prevention Bureau of the Ministry of Health and Welfare sent a administrative notice "Matter concerning the Implementation of the Leprosy-Free Policy" to the governor of each prefecture, instructing them to continue the "Leprosy-Free Prefecture Campaign." Private sanatoria were also included in this policy of enhanced segregation. It is egregious contradiction that this continuation and expansion of the "Leprosy-Free Prefecture Campaign" took place even in the mist of the rapid development of medical treatment by Promin, which made it impossible to deny that Hansen's disease could be cured. For instance, on November 27, 1948, in a meeting of the Health and Welfare Committee of the House of Representatives under the third Diet, Ryutaro Higashi, the director of the Medical Bureau of the Ministry of Health and Welfare, said that the

"(Former) Leprosy Prevention Law" should be modified so that less severe patients are allowed to leave sanatoria.

However, this proposal was overturned due to strong opposition led by Kensuke Mitsuda at a meeting of the directors of sanatoria on June 24 and 25, 1949. In the end, only the expansion of the "Leprosy-Free Prefecture Campaign" was agreed upon.

# 2. Hansen's Disease Patients under the "Leprosy-Free Prefecture" Campaign

On October 9, 1951, the "Standards for Admission to National Sanatoria" was modified under the direction of Ryugo Hashimoto, the Minister of Health and Welfare; while it said that the director of a sanatorium can order the discharge of a patient from the hospital "when treatment at the center is no longer necessary," it nevertheless adds, "except leprosy patients" (Director of the Medical Bureau, Ministry of Health and Welfare, "Establishing the Standards for Admission to National Sanatoria," October 16, 1951). On this point, if a tuberculosis patient was cured, the patient were allowed to be discharged from the sanatorium, but Hansen's disease patients were not allowed to be discharged from the sanatorium; it was the basic policy of the Ministry of Health and Welfare. Of course, in reality some of them were "released due to improvement." However, the policy of the Ministry of Health and Welfare was always one of lifelong segregation, and "release due to improvement" was not publicly allowed.

In 1951, the Health and Welfare Committee of the Upper House set up a "Subcommittee concerning Leprosy," and it held its first meeting on October 5, moving toward a revision of the "(Former) Leprosy Prevention Law." The post-war "Leprosy-Free Prefecture Campaign" led the public opinion to the 1953 revision of the "Leprosy Prevention Law," i.e. the issuing of the (new) "Leprosy Prevention Law," in which compulsory segregation was clearly stipulated.

# 13. Fusion of the Policy on Hansen's Disease and a Eugenic Policy in Japan #7

#### A. Birth Control of Hansen's disease patients

Sterilization procedure on Hansen's disease patients is said to have begun in 1915 when Kensuke Mitsuda, the chief physician of Zensei Hospital, operated on a male patient. Zensei Hospital, which had been founded in 1909, had the general rule that males and females were separated at the beginning. This was with the idea that preventing the patients from having children would prevent new cases of Hansen's disease. However, this strategy of birth control-by denying them sexual satisfaction by keeping male and female patients separate-failed, and Mitsuda was led to the more convenient method of sterilization for birth control. As a means of birth control, this sterilization was also a form of eugenic policy, but the way this was introduced was in a "conclusion-first" fashion. Eugenic questions such as whether or not Hansen's disease was an appropriate case for applying sterilization were never asked.

#### B. Marriages in Sanatoria, Used for Patient Control and Sanatorium Management

Mitsuda thus cut off the link between sex and reproduction by introducing sterilization. Sexual desire, which used to have interfered in managing patients until that time, was now used as a means to promote patient management. Mitsuda allowed sex between man and woman under the condition of sterilization. This made patient management easier as he tamed the sexual desires of the patients, but there was much more. The co-ed confinement, which was made compatible with birth control by means of sterilization, was now redefined as a new tool to give reason for "another life" of the compulsory segregation of patients in sanatoria. Mitsuda took full advantage of it. To Mitsuda's concept of a sanatorium, sterilization and marriage had very critical meanings.

Also Mitsuda and others thought that co-ed confinement would reduce the chance of infection to healthy people (through patient segregation) and also reduce the operating cost of the sanatorium. The segregated patients were assumed to support themselves through mutual cooperation and labor based on assignment by gender role. The attracting influence of female patients, relatively fewer than male patients, was considered useful in managing male patients, and the sex and the sexual role of female patients were used as a resource for sanatorium management. On the other hand, pregnancies were considered never allowed, and any woman who became pregnant was forced to have an abortion. Even if a baby was born, the woman could not live with the child in the sanatorium. Therefore, even from the reproductive point of view, the sex of female patients was a victim of the segregation policy.

#### **C. Emphasis on Patient's Consent**

In the process of expanding sterilization of Hansen's disease patients, doctors of Hansen's disease sanatoria, such as Mitsuda, and related government staff members had all sorts of excuses for sterilizing Hansen's disease patients. They include conditions worsening due to pregnancy and childbirth (medical reason), difficulty in raising a child (social reason), possibility of infection during childhood, infection in the womb, and body-type heredity (eugenic reason), etc. None of them was based on evidence. Therefore, in particular, an emphasis was given to "consent of the patient." The majority interpretation was that, when a mentally-competent person gave consent, unless it was against "public order and morals," the illegality of sterilization, even for non-medical reasons, could be exempted. Whether or not the "consent of a patient" in a Hansen's disease sanatorium really meant a free decision of the patient, was never asked. Behind the fact that the opinion of Mitsuda, et. al. (that sterilization was a free decision of the individual) was accepted, was the idea, shared even by Christian directors of sanatoria such as Riddel, that "Hansen's disease patients must not produce children."

Sterilization on Hansen's disease patients continued to be carried out as a fait accompli, even with the possibility that it was in violation of the Penal Law, and it was publicly approved several times by the government. According to a 1940 report by Nobuharu Aoki, an engineer of the Ministry of Health and Welfare, 1003 male patients had had vasectomies in Hansen's disease sanatoria across the country by 1939.

### D. Movement to Legalize Sterilization and Its Failure

By 1915, when Mitsuda began sterilization, Japanese scholars had already been introduced to eugenics and sterilization methods established in the United States. In negative eugenics, to which sterilization belongs, first "undesirable properties" in society protection were defined, and then they were linked to "heredity to descendents." Hence, what was seen as problematic included not only "heredity" in the narrow sense of the word but also "defamed seed" due to such reasons as vertical infection and alcohol. In other words, rather than the carefully verified scientific evidence of whether or not the disease is hereditary, priority was given to controlling the births of those with "undesirable properties." Since the 1920s, eugenics was supported by many intellectuals, and in 1927, a subcommittee on population and food problem under the Cabinet. Thus, sterilization "with the consent" of Hansen's disease patients was silently acknowledged without indictment.

The Ministry of Health and Welfare, set up in 1938, began immediately working on preparation of a bill for legalizing sterilization, led by the Eugenics Department of the

Prevention Bureau. In the following year, an "Outline of an Ethnic Eugenic System Proposal" was decided, under which "leprosy patients," along with patients of hereditary mental illnesses, were considered subjects of sterilization. The Bureau actually acknowledged the fact that requiring the sterilization of patients of leprosy, an infectious disease, is "out of line" with the intent of the Eugenic Sterilization Law, intended to prevent hereditary illnesses; however, Hansen's disease patients were included under this bill with the social excuse that the patients would have a difficult time raising their children. Later, responding to an answer of the General Assembly of the Citizen's Physical Fitness Council, in order to avoid the misunderstanding that leprosy is a hereditary disease, lawmakers decided to place sterilization of leprosy patients under the (Former) Leprosy Prevention Law. Thus, this proposal for a Revised Leprosy Prevention Law was sent to the 75<sup>th</sup> Parliament along with the bill of Citizens' Eugenic Law. In Parliament, debate centered on the contradiction between the ideology that the Citizen's Eugenic Law was intended to limit hereditary illnesses and the ideology of legalizing sterilization of patients of leprosy, an infectious disease, even under the Leprosy Prevention Law. Many critical opinions were given. As a result, the sterilization of Hansen's disease patients was never legalized. The Citizens' Eugenic Law itself was passed and went into effect, excluding Hansen's disease patients. Despite all this, the sterilization of Hansen's disease patients continued to be carried out as an already established fact, an exception to the application of the Citizens' Eugenic Law.

# **E.** Legalization of Sterilization of Hansen's Disease Patients under the Eugenic Protection Law.

After Japan lost the war, activists of childbirth control, who had had no option but to suspend their activities during the war, began their activities again. In 1947, the first post-war "Eugenic Protection Bill" was submitted by a member of the Diet belonging to the Socialist Party. Article 1 of the bill stated, "The purpose of this law is to protect the life and health of the mother and to prevent the births of defective descendents, thus contributing to the building of a civilized country." Under this bill, chief physicians of mental institutions and directors of "leprosy patient confinement centers" were allowed to submit a request to the Eugenic Committee to determine whether or not it is proper for a given person to be sterilized; if so determined, mandatory sterilization would be carried out. It is evident that the pre-war theory of human-body heredity and uncertain heredity concepts was taken over by the proposers of the Socialist Party's bill, led by OB doctors and activists of childbirth control, that leprosy is "hereditary." However the reason leprosy patients were objects of sterilization were not only due to "hereditary reasons." Many types of people who were considered to produce "defective descendents" for various reasons were objects of sterilization, including "ill and physically weak people, women who had given birth many times, and poor people,

whose children would become ill or weak or could become delinquent due to a bad surroundings" and "those with a severely pathological personality, alcoholism, or other addiction difficult to heal" (Article 3). The situation at the time wherein eugenic objects were widely defined served as background of the bill.

A point to note about the Eugenic Protection Bill submitted by the Socialist Party is that a shift had been made to mandatory sterilization requested by directors of "leprosy confinement centers." Even a memorandum of the Population Problem Research Meeting in October 1947, which criticized the Eugenic Protection Bill, affirmed the idea of mandatory sterilization of Hansen's disease patients. After the war was lost, the idea of enhancing the eugenic policy to build a "civilized nation" was very strong among population policy makers and doctors at the time. Also those days saw the beginning of post-war Leprosy-Free Prefecture Campaigns, and the idea of promoting compulsory confinement of Hansen's disease patients was gaining wide popularity, certainly influencing the eugenic policy discussion as well.

The proposed bill of Socialist Party was not passed, but in 1948, a new Eugenic Protection Bill was submitted to the Diet by a multi-party team of representatives, led by Yasaburo Taniguchi; the team included the Socialist Party member who had submitted the previous bill. This time, the bill was passed. Section 3 of Article 3 of this new Eugenic Protection Law defines the extent of application of optional sterilization, including the clause "if the person or the person's spouse has leprosy and it may be contagious to the person's descendents." While it went on to say that leprosy "currently belongs to infectious diseases," the explanation was very ambiguous: "it is possible that some have less resistance to leprosy due to hereditary reasons." Incidentally, in the censorship stage of this Eugenic Protection Bill, prior to its submission, the Government Section and the Public Health Section of GHQ made many remarks and suggestions for the bill, especially concerning the mandatory sterilization problem; however, they seemed to have no problem with voluntary sterilization, including its application to Hansen's disease. Even the debate in the Diet did not even touch the validity of sterilization of Hansen's disease patients. The Japanese Constitution having been established, the government determined that it would be difficult to maintain the fait accompli of sterilizing Hansen's disease patients unless an action was taken of new legislation. Taking advantage of the massive confusion of unprecedented food shortage immediately after the war, the government not only legalized sterilization but abortion also.

According to a statistical report on eugenic protection, one of the post-war characteristics was that the number of females sterilized was much larger than the number of males sterilized. Statistics on sterilization procedures and abortions according to prefecture show that Kumamoto and Aichi prefectures lead in these numbers. This suggests that sterilization and abortions were carried out not only in areas where sanatoria were located but also in areas without sanatoria, where -on account of

Hansen's disease- these procedures were performed on patients who were not in sanatoria and on the spouses of patients. These facts also reflect the influence of Leprosy-Free Prefecture Campaigns.

Such a choice of life should be considered an extreme profanation of human dignity, but this did not change even after Mitsuda's death, at least until 1996.

# 14. Clarification of the Overall Picture of Damage due to the Compulsory Segregation Policy on Hansen's Disease #8

# A. Implementation of Damage Study

The Verification Committee concerning Hansen's Disease Problem and Research Panel established the Damage Study Unit and carried out the "Fact Verification Task concerning Hansen's Disease Problem: Field Survey on Damage" beginning in July, 2003. The study took about a year, and the Unit obtained valid responses from aggregately 841 people. 758 of these people were those living in the 13 national sanatoria for Hansen's disease across the country; 9 of them were those living in two private sanatoria for Hansen's disease; 69 were those who had left sanatoria for Hansen's disease; and 5 were family members. The purpose of the study was to "clarify the overall picture and characteristics of the damage resulting from the Hansen's disease segregation policy, chronicle the historical error of the Hansen's disease segregation policy as solid facts, and to make the study serve for recovery from the damage and for reccurrence prevention." In this section, we put together the study activities in the four areas, and describe the meaning of the study and its characteristics as well as the characteristics of the damage concerning Hansen's disease problem that the study has found.

# **B.** Meaning of the Study and Its Characteristics

With respect to the damage concerning Hansen's disease problem, there exist an enormous number of reports, autobiographies, literary works, etc. that seems to contribute to clarification of those damage. However, there have not been many studies like this study we have carried out, in which damage was studied from multiple perspectives and in a comprehensive manner. The meaning and characteristics of this study are as follows:

# 1. Extent and Scale of the Study

This study spanned the 13 national sanatoria, 2 private sanatoria, those who had left sanatoria, and their families, in an attempt to grasp the reality of damage to an unprecedented extent and scale. This was not possible in preceding studies, and needless to say, it is much larger in scope than the plaintiffs in the Hansen's Disease Government Liability Lawsuits. No studies concerning former Hansen's disease patients, domestic or international, have been as extensive as this study in scope or scale.

# 2. Method and Contents of the Study

This study, particularly in the area of surveying those living in sanatoria, used both a quantitative, statistical analysis and a qualitative analysis through interviews simultaneously. This was an attempt to understand the truths of damage that were long-term and multi-faceted, impacting the entire life (referred to as "lifetime damage"). Through this, the study reveals the universal nature of damage over all those studied; at the same time, it also shows the uniqueness and quality, i.e., depth and severity of the damage.

# 3. Study Cooperation

This study is an objective study based on sound scientific method in order to reveal the realities of existing damage. However, at the same time, a very large number of people of various backgrounds have participated and cooperated with us in this study of policy verification. First of all, there are victims themselves-the All-Japan National Hansen's Disease Sanatoria Residents' Association, the self-governing association of each sanatorium, and individual residents themselves-who participated and contributed to this study in many different ways, from the design step of the study to being interviewees. Next, professional organizations of social workers, led by the Association of Professional Organizations of Social Welfare, gave us full cooperation in our interviews in spite of the various difficulties they had as interviewers. Further to this, there were many volunteer collaborators who worked as "study assistants" with confidentiality obligation; they did many low-key post-interview tasks ranging from entry and organization of the large amount of information received from questionnaires to audio-typing tasks. In addition, the study was an attempt carried out by these collaborators in that, trying to encourage participation of every resident in each sanatorium as well as many former residents, it sought not only extracting the damage, but also providing an opportunity where each individual speaks about the life history. In each step of this entire study project, opportunities were provided to the many people -who participated and cooperated in various aspects of our study- to realize the need for awareness concerning the size and seriousness of the Hansen's disease problem and to see the reality of it. This has not only impacted social awareness concerning the implementation of medical and welfare policies of our country in the future but also contributed significant power toward recovery from the damage and prevention of future recurrence of similar problems. These facts suggest that this study project has accomplished the joint work of many people involved in various facets of problems concerning Hansen's disease in this country, the object of the study and the verification, and that it has provided a shared place for the human resource basis and social recognition toward continuous evaluation and improvement concerning the policy in question.

# C. Limit of the Study and Future Challenges

On the other hand, we must recognize the fact that this study, as the task of Field Survey to grasp the reality of the damage concerning Hansen's disease problem, has left certain challenges for the future. Even though we asked the approximately 3500 residents of the 15 sanatoria nationwide to participate in our study, participants were limited to only those who volunteered of their own will. Also, because our study emphasized the point of listening directly to the life story of participants, participation was limited to those who were capable of being interviewed. Many of the patients older than the survey participants, who probably went through more oppressive damage than anyone else, were living in buildings for the disabled or in hospital rooms, and were difficult to interview. The final number of people who participated in our study has reached 767, but, relative to the total number of residents, this is only about 1 out of every 4.5 people. A similar problem existed with our study of former residents and families, the types of participants whom we thought would be difficult to find from the beginning. At the end of October, 2004, immediately after the survey, the recipients of former-resident stipend numbered about 1300. Out of these we obtained only 69 valid interviews, which is only a handful. It goes without saying that a large number of victims remain unknown within families of Hansen's disease patients as this study has shown that some families suffered just as much damage as the patients themselves. In this sense, this study has only scratched the surface and seen a glimpse of the deep and dark cave of the damage. There are many areas that still remain unknown. However, the difficulty that the participants had in coming out and speaking of the damage they suffered and the "reticence" of former residents and family members as they carried out their social daily life-they themselves indicate the severity of the damage suffered and the continuity of damage that has lasted to this day. One former resident responded: "If they ever find out, I plan even now to sit on a JR railroad track with my hands put together (praying), even though I know this will cause trouble to JR." (male, placed in sanatoria in 1944). Further damage study is necessary, based on the social conditions behind such "preparedness"

Additionally, concerning those who did not enter sanatoria, we assessed methodology as well as schedule-related and finance-related conditions required to obtain survey participants of a certain scale, but gave up the idea. Damage suffered under the policies for Hansen's disease in Korea and Taiwan during colonization by Japan is also considered to play a critical role as historical validation. We hope and look to future study activities on these points.

#### D. Overview of the Reality of Damage concerning Hansen's Disease Problem

The reality of damage that the study has found is described in detail in various reports contained in the separate document "Survey Report of the Reality of Damage

concerning Hansen's Disease Problem." The real goal of this study should be to understand the multi-faceted reality for each person and position described in that document, but here we point out 10 items that structurally characterize the reality of damage concerning Hansen's disease problem, in order to present its outline.

# 1. "Social Damage" and "Residence Damage"

By comprehensively summarizing the damage discovered in this study concerning Hansen's disease problem, one can see that there are mainly two types of damage: one may be called "social damage" suffered in social life, and the other may be called "residence damage," coming from living in sanatoria. Damage concerning Hansen's disease problem can be considered combined damage, consisting of these two main types of damage among others. In other words, it has been actualized as suffering, and special burden and disadvantage experienced in every aspect of life as a human being through life in a sanatorium and life as a member of society, based on the experience of being a patient of Hansen's disease and of institutionalization in a treatment facility for Hansen's disease. There we see a variety of mental, physical, and life difficulty, financial damage, physical damage, psychological damage, and multi-layered and complex damage as "lifetime damage" as a whole, including the "violation of the right to live peacefully in society."

# 2. "Social Damage"

"Social damage" occurred in the framework of the prefecture level "Leprosy-Free Prefecture Campaigns", promoted by the national government, as well as the "recommendation to enter sanatoria," which completely ignored patient privacy in the local community. Fear and hatred of society toward Hansen's disease due to the above framework situation led to discrimination and prejudice against Hansen's disease patients and their families, which has caused, and is causing, interference and difficulty in their general social life, such as school admissions and employment(; some continue to this day). We can refer to these as "social damage."

# 3. "Residence Damage"

With this "social damage" as background, Hansen's disease patients, subjected to "compulsory confinement and segregation," were given no choice but to be treated in an "anti-medical or non-medical" fashion or "anti-welfare, non-welfare" fashion inside sanatoria. This caused their living and physical conditions to become worse, and these worsened living and physical conditions led to further differences between the living and physical conditions of patients and of the general public. Such differences have caused, and is causing, interference and difficulty when the patients attempted to return to the general public(; some continue to this day). We can refer to these as "residence damage."

#### 4. "Complex Damage"

One thing to keep in mind about "social damage" and "residence damage" is that these types are not independent and separate types of damage. In fact, they are both rooted in the public-health policy of "compulsory confinement and segregation" of patients in order to "protect the interest of the majority general public by sacrificing the few Hansen's disease patients." It is possible to conclude that, in this policy whose intent is to "separate" Hansen's disease patients from the society, these two types of damage create complex damage, in a mutually complementary manner. It is important to note that particularly after the war, when, under the Japanese Constitution, the "compulsory" physical means was technically denied and yet the main concept of "separation" was maintained as a policy by limiting the places of medical treatment and welfare on Hansen's disease to sanatoria, and this has made such complex damage essentially continue to this day.

#### 5. "Self Suppression, Self Discrimination"

It is important to note that, accordingly, the 'few,' i.e., the Hansen's disease patients, were denied any possibility of active resistance against their treatment based on the public-health policy (no option except some passive resistance), then "self suppression and self discrimination" has been produced, in which they have had no option but simply accepted the discrimination and prejudice of the general public, the poor environment within sanatoria, and even "compulsory confinement and segregation" themselves.

#### 6. "Extension and Continuation of the Damage"

It is also important to note that these damage did not stop at the Hansen's disease patients but that they also impacted their families and relatives. The families were forced to face with the choice-whether to choose to be on the side of the patient, who became victims of multiple types of damage, or to be on the side of the society, which was the foundation on which these types of damage were formed in a complex way. To be on the patient's side means to suffer the same damage as the patient; on the other hand, to be on the side of the society is to bear a burden to "cut off" their own relationship with the patient, i.e., to participate in the "separation" themselves as an assailant. Some patients even "took the initiative" to submit themselves to the confinement just so that their families would not have to face the painful choice. This type of "damage extension" to families and relatives needs to be noted. Further, the study has made it clear that the damage is not just in the past but "continuation of the damage" remains even today, as seen in the difficulties for patients to return to society, such a situation as when a patient tries to take a stand against the burden that is forced upon them, society does not show its understanding. This continues to the present.

7. "Damage" That Worked as a Force of "Discrimination" and "Separation."

"Damage" works as a force of "separation" and "discrimination." Such an unhappy situation was not rare. "Sterilization" was no exception. When a male placed in sanatoria submitted an offer to marry a woman, he was forced to make a decision between marriage and sterilization. However, in sanatoria, the number of female patients was much smaller than the number of male patients, so there were a lot of male patients who did not even face such a painful decision. "Sterilization" itself could be a trigger for "separation" and "discrimination" to those living in sanatoria. A similar problem occurred in "patient work" by residents. The extremely poor living standard of the sanatoria forced the patients to live an almost self-providing lifestyle, and, consequently, patient work included all sorts of labor. There were tasks that were relatively easy and the pay was relatively good; many patients wanted those. In contrast, there were "nurses" who had to stay with patients in severe conditions and those who cremated dead patients; these were hard and cruel jobs that no one took voluntarily. Such a variety in labor worked as a force to create "separation" and "discrimination."

### 8. "Tolerance of an Segregated Society"

Another thing to remember is that "compulsory confinement" and "absolute segregation" caused Hansen's disease patients to be "cut off" from the society, and ultimately this damage culminated in the formation of communities inside sanatoria where only Hansen's disease patients and former patients could reside and where there is a sense of completeness. By entering such a community, a patient was "cut off" from the existing family and regional communities and relationships therein. Instead, human relationships within the closed space of the sanatorium were formed. There, a separate and independent society was patterned, where the people say things like "in this sanatorium..." and "here, this is how things are..." The basic acts of normal life in a normal community, such as going to school, getting a job, falling in love, getting married, and even clothing and food were suspended by placement in sanatoria, and they were restarted or "created" in a new form inside the sanatorium. There, although similar activities were carried out on a similar scale like in a normal society, such as education, labor, love, marriage, pregnancies, sickness, aging, nursing, and funerals, these were undoubtedly patterned based on the policy intent of "lifetime segregation and confinement," a fact quite evident from the lack of childbirth and child-rearing. This fact was revealed by an extreme fluctuation of expressions described by the survey participants concerning their impression of sanatoria, from negative expressions like "places where we are not treated like human beings," "exile," "prison," "hell," and "colonies" to positive expressions like "places of fun life," "the best place," and "heaven." Further, about half of the survey participants have experienced the use of an alias, which is another indication that, despite some deficiencies, a society formed within the sanatorium by "cutting off" all relationships with the society and had a certain sense of completeness. It is worth noting as a basic structural element of the damage that, with "social damage" as background, there was no choice but to tolerate such a "segregated society" with critical deficiencies and to comply with it.

# 9. "Policy on Hansen's Disease and the Social Life Restarted"

It should be noted that sufferings in social life that started after the experience of living in a sanatorium and its heavy burden and disadvantages are generated in connection with the link between medical and welfare measures centered on sanatoria under the policy for Hansen's disease and the patient's life after leaving the sanatorium. This is true for both current residents and former residents of sanatoria. Because the places for medical and welfare benefits were limited to the sanatoria, many former residents of sanatoria had no option but to suffer various types of sufferings to avoid the impression of "medical treatment of a special disease at a special hospital." Some have hidden the fact that they have the disease or the fact that they have been at a sanatorium from their family and people around them. Some have hidden their past when they apply to a school or job and yet must spend their own funds to get treated at a sanatorium. Some, due to the necessity of disclosure of their history, have been forced to give up some benefits that are duly theirs. In this manner, many types of damage have been caused in the social life of those who have left sanatoria. Further, it should be noted that many who have experiences of living outside sanatoria see such physical and psychological sufferings, burden, and disadvantages as trigger of relapse and re-entry into the sanatorium. This is nothing but a process that results in "lifelong damage" through "re-production of damage."

# 10. "Mercy Welfare View"

It should be pointed out that, at the same time, the extended differences in living and physical conditions between general public and the communities within sanatoria, caused by "compulsory confinement and segregation" cause many people in the general public to give their compassion to these patients as living in segregated confinement for the benefit of the entire nation; however, once the patients' existence or actions go beyond the stipulated boundary (based on the presupposition that their lives were "cut off" from the society), the tolerance or pity initially held by the general public to the patients could turn to hatred as if toward enemies. Such a view can be called the "mercy welfare view" as seeing the residents of sanatoria as foreign objects in their living and physical conditions, with the idea that the patients' participation in the society is an act of "mercy," and the idea that imposes a certain boundary on the extent of patients' participation (or considers it abnormal for patients to step out of the boundary). It should be noted that such a view makes up the foundation of the "structure of damage" that makes the damage continue or re-occur even today.

# 15. Verification concerning Samples of Fetuses Left in National Sanatoria across the Country #9

### A. Overview of the Conditions

National sanatoria for Hansen's disease throughout the country and the Research Center for Hansen's Disease of the National Infectious Disease Research Center (hereafter referred to as the "Research Center for Hansen's Disease") have a large number of samples, in formalin, of fetuses and newborn babies (hereafter referred to as "fetus samples") resulted from artificial abortions, natural miscarriages, and artificially induced births (hereafter referred to as artificial abortions, etc.).

It is clearly known that eugenic operations at sanatoria for Hansen's disease began at Tama Zensho En by Kensuke Mitsuda in 1915. Whereas eugenic operations were carried out as a prerequisite to marriage in sanatoria, it is estimated that there were a significant number of pregnancies in sanatoria despite the efforts of Mitsuda, etc. Based partially on the fundamental principle of segregation and extermination of patients, sanatoria for Hansen's disease generally did not allow any childbirth or child-rearing except for very rare cases. Hence, sanatoria seemed to have no choice but to carry out abortions, etc.

Due to the lack of legal stipulations, etc., many of the fetuses produced were probably stored in the sanatoria. It is possible that some of them were provided for research, etc. and discarded, but between the 1930s and the 1950s, many fetuses ended up being left at the sanatoria for no purpose, submersed in formalin.

Among the items of this verification task, nothing has damaged and continued to damage the human dignity of residents more than the problem of these fetus samples.

#### **B.** Purpose of Verification

Concerning the fetus samples stored in national sanatoria for Hansen's disease and the Research Center for Hansen's Disease, we have scientifically verified them and express our opinions from medical and legal viewpoints.

# **C.** Methods of Verification

The Verification Committee carried out the verification concerning samples of fetuses at national sanatoria for Hansen's disease and the Research Center for Hansen's Disease according to the following schedule (the numbers indicate the number of samples of fetuses, etc.):

#### June 25, 2003: National Sanatorium Oku Komyo En 49

November 12, 2003: National Sanatorium Hoshizuka Keia	17
i En	
December 8, 2003: Research Center for Hansen's Disease	2
of the National Infectious Disease Research Center	
March 1, 2004: National Suruga Sanatorium	10
June 1, 204: National Sanatorium Matsuoka Hoyo En	1
July 31, 2004: National Sanatorium Tama Zensho En	35

# **D.** Results

The six facilities listed above are the ones with fetus samples today. Each one has between 1 and 49 fetus samples, with a total of 114 samples. A period when artificial abortions, etc were performed and resulted in those fetuses left was between 1924 and 1956, a period of about 32 years. The exact dates of about 50% are unknown. Many of those where the dates are clear are from 1935 to 1944, followed by the decade from 1945 to 1954. About 29 of the 114 fetuses are past 8 months (32 weeks) from conception, estimated by their lengths. Among those, 16 of them are estimated to have been born after 36 weeks. The percentages are 25.4% and 14.0%, respectively. In other words, even a conservative estimate shows that at least 25% are not the result of abortions but of either induced early births or natural, mature births.

#### **E. Remarks**

# 1. Medical Remarks

We here add some medical remarks concerning reasons for these fetus samples left. One theory is that they were left for research purposes. Among research topics using the fetuses are studies concerning vertical infection and studies concerning deformation of babies due to medication used for Hansen's disease. However, our actual verification shows that information about the fetuses, such as the dates of the abortions and parents' names, is either completely missing or incomplete on more than half of the fetus samples. This fact makes this theory (the idea that they were kept for research) very improbable. In addition, about 80% of those fetuses show no cuts for the purpose of research. A more likely explanation is that, aided by the lack of laws concerning how to discard medical waste, the fetus samples have been left without any purpose or application.

We also verified the facilities and environment where the fetuses are kept; the way they are managed is very sloppy and very unscientific.

The most important thing to note about this verification is the sense of medical ethics missing in national sanatoria for Hansen's disease, etc. It is particularly frightening that physicians lacked ethical sense and conscience; these things are still impacting today's sanatoria to no small extent.

#### 2. Legal Remarks

An important thing to remember from the legal standpoint is that the laws to be applied are different depending on whether or not the fetuses were still-born or born alive. Where a fetus was born dead, the question is whether its procedure was in compliance with the law. Where it happened prior to the 1948 Eugenic Protection Law going into effect, there had been no law justifying artificial abortions, etc on the basis of Hansen's disease. 60% or more of the fetus samples for which the dates are clearly given were made prior to July 1948, so these fetuses were robbed of life by a medical act incompatible with the law. In addition, before AND after the enactment of the Eugenic Protection Law, the fact is that abortions at sanatoria of Hansen's disease were directly or indirectly mandatory. If so, even if the Eugenic Protection Law formally justifies the abortions with consent, they were actually abortions without consent, which are essentially illegal.

In contract, if a fetus was born alive, the question is how the life was stopped after the birth. It is extremely difficult now to speculate how it was done, but there are some cases where the only imaginable thing is, at least for some newborn babies, that workers at sanatoria were committing murders in the sense of the Penal Law. Further to this, there are several testimonies that confirm such facts.

Making samples of fetuses, naturally, also involves legal matters. Keeping dead bodies (including bodies of 4-month-old fetuses) as samples requires compliance with the Corpses Preservation Law. If the fetus is less than 4 months old, then it must be treated as a medical waste. Either way, the basis for a corpse to be kept as a sample requires approval of the surviving family, but our study has verified that no facilities have any such approval documentation. Further, the purpose of making a sample should be "when it is particularly necessary for medical education or research," but the fetus samples found this time do not fall into either of these categories.

#### F. Pathological Samples, etc.

In this study we have carried out our verification with a focus on fetus samples left at sanatoria for Hansen's disease. However, we have also discovered that even the pathological samples kept in these places in a similar manner also have some major problems. Pathological samples include samples generated by autopsies of corpses as well as body parts extracted by surgery as a result of a medical procedure.

First, we studied reports on pathological samples at Nagashima Aisei En, Oku Komyo En, etc. Up to about 1980, the ratio of the number of samples due to pathological autopsies to the number of people who died in these two sanatoria is at least 90%. In other words, one can speculate that, at least up to that time, the concept

"patient death equals a corpse autopsy" was accepted as a "norm" among the residents, almost as a mandatory requirement. Such a frequency for pathological autopsies is an unimaginable proportion in normal hospitals.

At Tama Zensho En, Oku Komyo En, etc., along with the pathological samples, there are many other surgery-extracted body parts randomly placed in large polyethylene buckets in a careless manner. In such cases, information to identify individuals is mostly lacking.

Overall, the problem of fetus samples is extremely awful, but equally awful are the pathological samples produced by surgery and medical autopsies of corpses. The reason that this is so awful is that it is clear that this particular problem of corpse autopsy was a huge, long-lasting problem for all of the residents. The unseen pressures in making children sign their own "approval for corpse autopsy" when they enter the sanatoria, as well as the idea "death equal autopsy" was extremely cruel.

### **G. Recommendations**

First, the human right of a dead person concerning the reason for death is public order and is independent of animus quo of a private person. In accordance with this, concerning those fetus samples that may have been the bodies of babies who died after having been born alive, the Ministry of Health, Labour and Welfare should, considering the opinions of residents, the All-Japan National Hansen's Disease Sanatoria Residents' Association, and others, on the basis of the results of this verification, express to the related authorities the opinion that these authorities petition for postmortem examination by a coroner or submit reports of abnormal corpses.

Second, national sanatoria for Hansen's disease and the Research Center for Hansen's Disease are not special organizations but exactly identical to any other medical facilities in terms of medical ethics. Not only fetus samples but also surgery-extracted materials should be handled appropriately: those for which memorial services are to be respectfully held (dead fetuses at least 4 months old) are to be so carefully commemorated and cremated, then those that are to be enshrined collectively in charnel houses or other appropriate places should be so enshrined, and those that belong to medical waste (dead fetuses less than 4 months old) are to be appropriately handled as infectious wastes unless otherwise stipulated by any applicable municipal ordinance.

Third, pathological samples are to be handled appropriately now; every sample without individual information and every sample with or without individual information that is at least 10 years old (this is in accordance with the standards of the CAP (the College of American Pathologists of the U.S.), used in most university hospitals, etc.) should be processed according to standard procedures. Management of pathological samples at national sanatoria for Hansen's disease needs to be fundamentally reviewed.

Fourthly, as for medical ethics, it is undeniable, even now, that the level of ethics at national sanatoria for Hansen's disease is extremely low. These national sanatoria should be exactly the same as other medical facilities and thus cannot be forgiven for lack or insufficiency of ethical awareness in medical ethics. Just as they would not be excused if the quality of their medical treatment itself in the sanatoria were low, they should certainly be required to make improvements in their ethics. In particular, ethical education of physicians, who play a major role in medical practice, is a crucial challenge.

At any rate, the 114 fetus samples, many surgery-extracted materials, and over 2000 pathological samples, all resting in silence at national sanatoria for Hansen's disease, etc. -what are they saying to us quietly? Are they not powerfully asking us the question "What have they done?"-to all those who have been involved in the medical treatment of Hansen's disease in this country until now? Even if these corpses are carefully commemorated and respectfully buried, these facts must never be trivialized or forgotten by any means.

# 16. History and Reality of the Medical and Clinical Practice of Hansen's Disease #10 (\_1~6)

### A. Medical Science and Policy on Hansen's Disease

Learning from the irreversible crime of the modern policy on Hansen's disease in this country, we the citizens have the responsibility to create a society in which patients of infectious diseases are not removed as dangerous being and in which patients and families of hereditary illnesses are not discriminated against as special people with inferior genes. To this end, each one of us must have correct medical knowledge concerning Hansen's disease. What is important in this regard is to firmly maintain the position that no discrimination on the basis of sickness-whether infectious or hereditary-is excusable.

#### **B.** What Is Hansen's Disease?

Three factors are involved in the incidence of Hansen's disease. First, the human body is infected by the leprosy bacillus (Mycobacterium leprae). Of course, just because someone is infected with the leprosy bacillus does not mean that the person will have Hansen's disease immediately. The disease incidence is extremely rare in Japan, and it is not unusual that over 10 years lapse between the bacteria infection and the appearance of symptoms. The reason that infection often does not lead to the disease itself is due to proper functioning of the protective immune system. The disease manifests itself when this protective immune system does not properly function, but, according to recent studies, this has both a hereditary factor and a non-hereditary (acquired) factor. The former is something that came from the parents and thus does not change throughout life; this factor, when affected by the work of the acquired factor developed after birth, causes an immune-system failure, leading to the disease. When the society gets wealthy and the living conditions of the people improve, this acquired factor gets reduced, thus decreasing the chance of this factor affecting the hereditary factor to cause an immune-system failure. In 2003, the number of new patients in Japan was one. The probability that a person gets Hansen's disease in Japan today is less than 1 in 10 millions, and even if by any remote chance someone does get the disease, powerful medicines have been developed so that the disease can be completely cured on a outpatient basis by multi-drug therapy. There are also many instances where recovery in the immune system has naturally cured the disease and where the progress has been stopped naturally. If medical treatment is delayed, some physical damage may remain even after the patient is completely cured of the disease, making the patient's life inconvenient. But such disablement is simply a sequela. It is a myth to believe that Hansen's disease is incurable (by seeing such disablement) or to believe that the disease

is "contagious." What is important for the society to do instead is to get in touch with former patients from the standpoint of welfare for the disabled. Educational activities about Hansen's disease must correctly communicate these truths to the people.

### **C. Clinical Medical Science**

Clinically speaking, Hansen's disease is a chronic bacterial infection that manifests itself long after an individual body gets infected with the leprosy bacillus but shows no symptoms. Eventually the peripheral nerves and skin get damaged, and various levels of perception and motion paralysis may cause physical disablement. Because of these symptoms, for thousands of years, patients of this disease have been suffering various sorts of social discrimination, prejudice, and persecution. From the epidemiological standpoint, prevalence of Hansen's disease varies significantly from group to group, and even within a single group, the conditions change drastically over time. The immune resistance against Hansen's disease of a particular group is the sum of the immune resistance of each member of the group, so the same level of leprosy-bacillus infection could produce few patients among a group with many members with strong immune system and many patients among another group with a few members with strong immune system. Within one group, as the socio-economic conditions improve, the number of members with strong immune system increases, and the infection dies down naturally (and conversely, the infection may spread if conditions worsen). Hence, the infectious power of Hansen's disease appears to change because of the change in the acquired factor that is related to the incidence of the disease. Today in Japan, the probability of someone infected with Hansen's disease is infinitesimally small, bordering on zero.

# **D.** Birth and Development of Modern Medical Studies and Treatment for Hansen's Disease

Modern medical studies of Hansen's disease began in Norway in the late 19<sup>th</sup> century. Back then, the accepted theory was that it is a hereditary disease. However, with the discovery of the bacillus by Dr. Hansen, it was proved to be an infectious disease, and the so-called "Norway method," a mild isolation policy with consideration of human rights of patients, was internationally accepted. The "Norway method" consisted of the following four pillars:

- (1) Hansen's disease can be prevented by popularizing general public hygiene.
- (2) Isolation of Hansen's disease can be sufficiently carried out at one's home.
- (3) If a poor family cannot sufficiently carry out isolation at home, a national hospital shall aid in the isolation.
- (4) Homeless people shall be absolutely isolated whereas others are optionally

isolated.

As seen here, the isolation of patients was the basis of preventing Hansen's disease. However, as the medical understanding of Hansen's disease advanced, the isolation policy became more humane, leading to a hybrid method using both outpatient treatment and hospitalization in order to reduce the negative effects of isolation.

Chemotherapy of Hansen's disease was established in the 1950s when Dapsone began to be used successfully to treat the disease; since that time, Hansen's disease has generally been treated on an outpatient basis at a general hospital. Further, it was proved later that patients being treated with chemotherapy are not contagious. As a result, in the 1960s, even isolation for the purpose of infection prevention was totally abandoned and "Leprosy Prevention Laws" were repealed in foreign countries. With the repeal of prevention laws, sanatoria for Hansen's disease lost the legal ground for their existence, but no sudden changes were made in the system; rather, for those patients who could not go back to the society for a variety of reasons, the sanatoria were not closed. New patients were treated on an outpatient basis, and those who wished to continue staying in sanatoria were guaranteed housing. Consequently, while the number of residents kept decreasing due to return to society and deaths, generations change develops and they are in the process of turning to normal villages and towns.

In basic medical research of Hansen's disease, in 1960s Shepherd's "method for multiplying bacteria in isolated legs of a mouse" made it easy to develop new chemical medicinal treatments. In the 1970s, armadillos and nude mice were successfully used in studies of animal inoculation, and researchers were able to obtain new and fresh leprosy bacillus, indispensable for research. Supported by the rapid progress in immunology about the same time, the pathological immunological mechanism causing Hansen's disease was discovered, and in the 1980s, the introduction of molecular biological methods enabled medical research on Hansen's disease to be carried out as in other medical fields. The DNA sequence of all genomes of Hansen's disease was found in 2001, and it was shown that the genome size of a leprosy bacillus is 3.3 million base pairs, only 34 of that of a tuberculosis bacillus, and that many functions of critical genes have defects. It was also discovered that the leprosy bacillus possesses only the minimum genes necessary for survival and that it cannot breed without a host. With the sequence of entire genome found, now more studies concerning the survival and breeding of the bacillus and its genes are done, opening new doors for developing more effective medicines, etc.

In the field of eidemiological research, as the understanding of the hereditary element increased by genetical epidemiology, it was shown that the presence of an acquired factor is essential for the onset. Thus, the medical basis for why a change in the socio-economic conditions could affect the incidence of Hansen's disease was laid. More recent development of molecular epidemiology research is discovering even newer information concerning the infection source and infection mode of the leprosy bacillus.

# E. Birth and Changes of Medical Studies and Treatment of Hansen's Disease in Modern Japan

Japan's modern medical studies of Hansen's disease, begun in the Meiji Period, initially attracted many superior researchers. However, with the enactment of the Leprosy Prevention Law of 1931, followed by the forceful progress of the Japanese-style absolute segregation policy propelled by Leprosy-Free Prefecture Campaigns, the interest of researchers quickly departed from Hansen's disease. Consequently, medical studies of Hansen's disease were dominated by the self-righteousness of a few doctors and non-scientific theories, and they were reduced to nothing more than a tool for the government supporting the national policy without criticism. As for medical treatment, the innovative effect of Promin was proved even in Japan soon after the war, and an age of advanced chemotherapy began, but compared to other countries, switching to the oral medication of Dapsone was late, further delaying patients' return to the society. The main reason for this delay is that related people did not have awareness toward patients' return to the society and medical treatment outside sanatoria until much later. Beginning in the 1970s, Japanese sanatoria began using Rifampicin and Clofazimine. Today, the standard is WHO's multi-drug therapy, and most patients in sanatoria are not taking anti-Hansen's disease medication except a very few recurring patients.

Medical treatment (at the sanatoria) for illnesses other than Hansen's disease suffered a devastating lack of quantity and quality because of the Japanese-style absolute segregation policy, which separated the medical practice at the sanatoria from general medical practice. The reasons for mandatory placement in sanatoria were supposed to be "to receive quality medical treatment" and "to have secure, peaceful life"; however, the quality of the medical treatment was severely low, and the disappointment of the residents was significant. The poor medical treatment and infectious diseases such as tuberculosis led to many unnecessary loss of life.

In order to achieve the Japanese-style absolute segregation and extermination policy, the Japanese government basically did not allow any medical treatment outside sanatoria. The medical treatment, which was administered for over 3500 former residents who had returned to the society, thanks to the progress of chemotherapy, and for those patients who were not placed in sanatoria, was actually never systematically defined until the repeal of the (New) Leprosy Prevention Law in 1996. As a result, many of those had no option but to return to sanatoria. The fault and liability for this are extremely serious.

# 17. Psychiatric Medical and Clinical Practice at Hansen's Disease Sanatoria #10 (\_7~8)

### A. Psychiatric Treatment at Sanatoria for Hansen's Disease

### 1. Double Discrimination

Psychiatric patients in sanatoria for Hansen's disease were doubly discriminated against. For a long time, the only treatment for the patients of mental illness was imprisonment and/or quarantine. It is expected that many of those died earlier than they should have while left in the state of imprisonment. Building of a psychiatric ward was opposed by other patients, and whenever a medicine for Hansen's disease or psychiatric disease became available, the psychiatric Hansen's disease patients received them very much later. It also appeared that their care switched from care by patients to the staff members' care very late. At facilities with a large number of inmates, naturally mental illnesses occur. It is thus essential that these sanatoria be staffed with full-time or part-time psychiatrists, but such an arrangement was also made very late, and even to this day, the situation is very insufficient.

It has been reported that tuberculosis patients were also discriminated against at sanatoria for Hansen's disease. It would be interesting to investigate how the discrimination differed between psychiatric patients and tuberculosis patients, but we were not able to study the problem of tuberculosis. At any rate, this problem of double discrimination-those who are discriminated against are also discriminating certain members of their own group-is possible to occur in the future, also, and further research is necessary.

Sanatoria for Hansen's disease were compulsory relocation camps. Naturally, at such places, forced confinement syndrome (or facility syndrome) would occur. In what form did it really come out? In the area of psychiatric illnesses, it manifested itself in an increase of hypochondria as patients kept becoming more introverted. The fact that many patients killed themselves is linked to this, also. Further, this must have appeared in inter-personal relationships and other psychological and behavioral ways, also.

On these issues, Mieko Kamiya, who dedicated herself to psychiatric treatment at sanatoria for Hansen's disease early on, attempted to find the answers by various psychological studies, but the research was insufficient to grasp the totality of compulsory confinement syndrome. Extensive socio-psychological studies should have been carried out earlier, but the chance was lost. Kamiya went to Nagashima Aisei En at a time when Hansen's disease was not known to be completely curable; her determination is to be unconditionally respected. However, Kamiya actually considered the existence of sanatoria of her day positive, and while she showed unlimited mercy and compassion toward those patients who would accept it, she was cold on those who were critical to it. This fact has already been pointed out and properly criticized. It is

probably appropriate to see Kamiya as a very dedicated psychiatrist under the Mitsuda regime.

#### 2. Symptoms of the Psychiatric Patients

In the past, it was debated whether or not there are mental illnesses unique to Hansen's disease patients. Today, as we know that the leprae bacterium cannot directly infect the brain, the existence of a "leper's mental illness" is denied.

However, Hansen's disease does accompany very severe nerve pains. Since the use of Rifampicin began, the incidence of nerve pain was considerably decreased. At Tama Zensho En, starting about 1932, morphine poisoning became widespread, and any patients found in possession of or use of morphine was placed in monitored cells. In some sanatoria, poppy plants were secretly grown. Even after the war, some patients continued to show dependency on pain-reducing substances. Such substances mainly used among patients seemed to vary according to sanatoria, as sepazon, sofmin, Pentazine, and Ravonal . Especially their request for injection at night made the job of overnight doctors difficult. Pentazine also affected the medicine budget of sanatoria. Dr. Saburo Harada attempted a nerve-pain therapy using acupuncture and was able to reduce the incidence of Pentazine-dependency significantly.

Examples of patients who became schizophrenic due to interning at a sanatorium are documented by Kamiya.

At Tama Zensho En, after 1960 when an alcohol ban was lifted, the incidence of Wernicke syndrome due to alcohol increased, according to Dr. Yoshisuke Nakagawa, who heard this from his predecessor.

Because of their physical handicap due to Hansen's disease, their mental illness had some special syndromes. More than a few of them needed someone else to take care of their financial management. This resulted in the incidence of "hallucination of things being stolen." Others had the victim's complex resulting from a sensory failure, such as erroneously thinking that the caretaker had brought in laundry that was not completely dry. Under normal circumstances, the "hallucination of things being stolen" by someone in a neighboring room is difficult to treat generally; however, by the authority of the sanatorium director, when one patient was moved from one room to another several times, the problem went away without incident, according to one report. Because of physical handicap, akathisia, which is a side effect of a medicine for mental illness, can show itself in the form of "upper-body shaking." Particularly severe is the fear faced when a patient is about to lose eyesight; some of them committed suicide. However, there were not many patients who sought psychiatric therapy due to blindness neurosis.

In the period when the sanatoria were closed to the society, the interest of patients also looked to within their own bodies, and in some periods remarkably many patients showed a tendency to be introverted. Some patients of schizophrenic disorder live quietly in sanatoria but away from everyone else, without having to show drastic