symptoms.

Treatment of depression seems to have gone rather well by anti-depressants prescribed by doctors in internal-medicine, without psychiatrists.

Recently, the number of specifically psychiatric problems has decreased while problems associated with aging are on the rise. More specifically, today's big problem is that more and more people are living in total seclusion as communication with others takes place less frequently as they age older. Progress in individualized rooms and independent housing eliminated things like common restaurants; was it really a good decision? Drs. Yoshisuke Nakagawa and Sachihiko Takahashi are questioning these things. What is wanted today is a measure to address aging in which mental richness, including inter-personal communication and exchange, can be brought back.

B. Psychological Damage of Hansen's Disease Patients

1. Why Suicide?

A key to understanding the depth of the psychological damage of patients of Hansen's disease is to find the answers to questions such as (1) how frequently the patients (and their families if possible to find) seriously thought of, planned, and attempted committing suicide and (2) at what level the former patients are still connected to their families and hometown. Here, we verify the situation concerning suicide. Suicide is a big issue as a psychiatric problem in sanatoria for Hansen's disease.

2. Suicide Rates Found in Statistical Documents

The following shows the suicide rates among the residents of sanatoria (incidence of suicide for every 100,000 residents). In general, we calculated the rates every five years. These rates have been calculated with respect to the sum of the numbers of residents (carried-over residents and newly institutionalized residents) for all the sanatoria that responded. These responses counted the same patient twice where the patient moved from one sanatorium to another in a given year, so the actual suicide rates would be higher than those shown here.

1909-10: 159.5　1911-15: 0.0　1916-20: 25.7　1921-25: 81.8
1926-30: 28.7　1931-35: 98.9　1936-40: 54.1　1941-45: 52.0
1946-50: 35.9　1951-55: 38.8　1956-60: 28.4　1961-65: 36.4
1966-70: 48.4　1971-75: 22.4　1976-80: 29.8　1981-85: 52.7
1986-90: 51.2　1991-95: 29.4　1996-99: 45.2

3. Suicide Rates for All of Japan

The suicide rates for the entire country have hovered around 20, with a minimum of 14.2 in 1967, but drastically increasing since 1998. According to the National Police

Agency, the number of suicide deaths in 2003 was 34,427, from which we obtain the suicide rate of 27.0 for the year, based on the October 1 population of 127,619,000. This could be supposed to be the largest rate in recent history. The number of suicide deaths given in the cause-of-death statistics by the Ministry of Health, Labour and Welfare is 2000 to 3000 smaller than those reported by the National Police Agency.

It is quite clear that, compared to these rates as shown above , the suicide rates in the sanatoria for Hansen's disease are higher. The characteristics of the change in suicide rates in the sanatoria can be summarized by "high ratios" up to the end of the war, "increase" between 1961 and 1970, and "re-increase" after 1981. Although it is not possible to say definitely what has caused these changes, it might be possible to see that the "high ratios" up to the end of the war indicates that suicide was a way to escape sufferings of confinement (including distress involving their families) and pain due to the disease (including severe nerve pains and fear of blindness), and the more recent "re-increase" may be caused by the aging of the residents.

4. Testimonies of Doctors

In *Psychiatric Research Concerning Leprosy* (1959), Mieko Kamiya stated that the suicide rate during the past ten years (1948 to 1957) was 1 while the sixteen years previous to that (1932 to 1947) had the rate of 2.1 (*Psychiatric Research 1* by the same author, Vol. 7 of the Collection, Misuzu Books, 1981). Here, figures like 1 and 2.1 represent the numbers of suicide deaths. Estimating from the average of 1 and 2.1 suicide deaths per year, we can conclude that Nagashima Aisei En had 34 suicides between 1932 and 1947 and 10 between 1948 and 1957. Kamiya also administered an essay-completion test to 230 non-hospitalized patients living in Nagashima Aisei En and discovered that 160 of the 230 patients were astonished with fear when they found out the name of their disease, and about 20% of them (14% of all of them) considered suicide. According to Sachihiko Takahashi, who worked as a psychiatrist at both Nagashima Aisei En and Oku Komyo En, about one-third to half of the residents from whom he heard directly had either planned suicide or had seriously considered committing suicide.

5. Testimonies of Those Who Recovered

We interviewed on the life story and disease history of 13 residents of Tama Zensho En (5 female and 8 male residents, ages 68 to 86; two of them were blind). These thirteen patients were relatively active people, but 6 out of the 13 had planned suicide or had thought of suicide very seriously. What led to their planned suicide or strong desire for suicide was the pain of being sick (3 patients, one of whom has a disabled hand), pain of being sick and no hope for the future, pain of being sick and abuse by husband (abuse related to having the disease), and the pain of being sick and having a socially devastating disease (each response by each patient respectively).

6. Study of the Reality of Damage on Residents in Sanatoria

As a part of the interviews of the Study on the Reality of Damage carried out by the Verification Committee, we allowed the respondents to speak freely about what they thought of when they were told of the disease. 77 out of 613 (12.6%) spoke of "death" or "suicide." It is also speculated that even among those who did not use these specific words, a large proportion of them had thought of suicide or death. Often it was a close family member who stopped them from committing suicide, but conversely some felt painful and sad as they were told to open a vein by their own family members. It is not difficult to imagine that more than a few people have actually chosen death in obscurity before they were to enter any sanatorium after the discovery that they had the disease. About 90% of the respondents said that they had either heard of or seen suicides in their sanatoria. Some of them think that the sanatoria were hiding the facts concerning suicides. As far as motives of suicide, they listed the nerve pains due to Hansen's disease, tendency for depression, and conflicts with close family members.

7. Conclusion

The suicide rates among those living in sanatoria were almost twice as high as the suicide rates of the country. According to what Usami (a committee member of the Research Panel) remembers, the actual numbers of suicides were far above those figures given by the sanatoria. Considering the responses of the Study on the Reality of Damage, it can be estimated that the suicide rates among the sanatorium residents were more like 3 times the rates of the entire country. There are also many cases where the disease led to suicide of a family member close to the patient. It is estimated that many patients committed suicide before they were to enter a sanatorium. It is reasonable to assume that a high percentage of the suicides in sanatoria were largely linked to Hansen's disease. All these statistics speak of the depth and extent to which the patients suffered psychological damage due to having Hansen's disease in this country.

C. Study Concerning the Mental Health of Residents of Sanatoria for Hansen's Disease

Below, we introduce several things concerning the current problems on mental health of those living in sanatoria for Hansen's disease: (1) a study covering residents concerning the level of living satisfaction, past experiences, and the current situations (2) a study covering the directors of the sanatoria concerning the reality of psychiatric therapy at sanatoria; (3) a study covering the psychiatrists working at sanatoria concerning the reality of psychiatric therapy there; and (4) a study concerning medication for psychiatric therapy prescribed for residents. Out of these, the first three are based on the reports of the subcommittee concerning Hansen's disease under the

Rehabilitation Committee of the Japanese Society of Psychiatry and Neurology.

1. Survey Conducted on Residents of Sanatoria for Hansen's Disease

The survey was conducted on the residents of sanatoria concerning their living satisfaction index K (LSIK), age, sex, time spent in the sanatorium, living conditions before, at the time of, and after entering the sanatorium, current physical and mental conditions.

LSIK is a self-reporting scale devised to measure the subjective quality of life (QOL-happiness in aging) specifically for seniors. It is determined that the higher the score, the better the subjective QOL.

Based on their informed consent, we asked those residents to fill out anonymous questionnaires.

We requested cooperation from the 13 national sanatoria for Hansen's disease across the country. We were able to obtain cooperation from the following five sanatoria-Kikuchi Keifu En, Tohoku Shinsei En, Tama Zensho En, Oku Komyo En, and Ohshima Seisho En. A total of 758 (out of the 1861 residents as of May 1, 2002) filled out questionnaires.

The average age of the respondents was 74.0 years old; the average age of entering the sanatoria was 20.9 years old, with the average stay of 50.2 years.

The LSIK score of the 650 residents at least 65 years of age was 2.3, and there were not significant differences due to sex, the number of years spent at the sanatorium, the dates when they entered the sanatorium, or the age when they entered the sanatorium. The tendency was that the older they were, the statistically higher the score was. Compared to the nationwide sample of all Japanese seniors, all of these scores were significantly lower than the national averages in every category classified according to sex and age.

Using logistic regression analysis, we analyzed factors related to the living satisfaction index K (LSIK) scores of the residents of sanatoria for Hansen's disease. Statistically significant correlation was found between these "low LSIK scores" and two factors: "No relationship with the family at home" and "thought of dying while living at the sanatoria."

2. Survey Conducted on the Directors of Sanatoria for Hansen's Disease

We also studied the need for a psychiatrist based on the responses by the directors of sanatoria.

We requested cooperation from the directors of the 13 national sanatoria for Hansen's disease across the nation. Eleven responded to us: Kikuchi Keifu En, Matsuoka Hoyo En, Kuryu Rakusen En, Tohoku Shinsei En, Tama Zensho En, Oku Komyo En, Ohshima Seisho En, Nagashima Aisei En, Amami Wako En, Okinawa Airaku En, and Miyako Nansei En.

Out of these, four had a psychiatrist working on site. Psychiatrists began working at these facilities between 1945 and 1989. At two of the facilities, the directors determined that a psychiatrist would be needed; the reason for the other two to have a psychiatrist was unknown. Out of the seven facilities without a psychiatrist, five of them responded that they need a psychiatrist, one responded that there was no need, and the other one responded "hard to say." This last one has a therapy cooperation arrangement for psychiatric patients with a nearby prefectural psychiatric hospital.

3. Survey Conducted on Psychiatrists Working at Sanatoria for Hansen's Disease

We asked the psychiatrists working in sanatoria for Hansen's disease concerning the number of patients for each illness according to the ICD-10 classification (classification of illnesses by WHO) of the patients they are treating, measures to be taken when mandatory therapy is necessary, and measures to be taken when a problematic behavior occurs not related to psychiatric disabilities.

We asked for cooperation from all the 13 national sanatoria for Hansen's disease across the country. Eleven responded to us: Kikuchi Keifu En, Kuryu Rakusen En, Tohoku Shinsei En, Tama Zensho En, Oku Komyo En, Ohshima Seisho En, Nagashima Aisei En, Hoshizuka Keiai En, Amami Wako En, Okinawa Airaku En, and Miyako Nansei En. However, out of these, six of them did not have any psychiatrist working on the premises, so the valid responses were obtained from the psychiatrists at the five sanatoria: Kikuchi Keifu En, Tohoku Shinsei En, Tama Zensho En, Nagashima Aisei En, and Hoshizuka Keiai En.

Out of the five sanatoria that responded, only three had a full-time psychiatrist. One another had a part-time psychiatrist, and the status at the other one is unknown. The full-time psychiatrists worked 2 to 3 days a week.

As for the number of patients these psychiatrists were seeing, we obtained the data from 4 of the facilities (one did not respond to this question). The total number of the residents at these 4 facilities was 2044; the psychiatrists were seeing 191 of them (9.3%), about 14.0 patients per day, or 91.0 patients per month. The breakdown according to the illness classification of ICD-10 is as follows: [F0] 2.7% of the residents had organic psychiatric disorders including symptoms (2.5% had senile dementia); [F1] 0.3% had mental and/or behavioral disorders due to use of a substance mentally affecting the user (all of them were alcohol-dependency); [F2] 1.8% had schizophrenia, schizophrenic-type disorder or hallucination disorder; [F3] 1.6% had a mood disorder; [F4] 2.0% had a neurotic disorder, stress-related disorder, or physical-expression disorder; [F5] 0.7% had a behavioral syndrome related to physiological disorders or physical factors; [F6] 0.05% were adults with behavioral disorders or personality disorders; [F7] 0.2% had intellectual disorders; and 0.1% suffered from epileptic seizure (not classified under the F-code). One case of alcohol-dependency and one case of stress-caused gastritis were found as symptoms related to the incidence of Hansen's disease and/or living in a sanatorium.

When these ratios with respect to the total number of residents at these sanatoria are compared with the corresponding ratios among the senior citizens of Japan, there was no difference in F2; ratios for senile dementia, F3, F4, and seizure were statistically significantly lower.

As for measures to take for patients who need to be restrained due to psychiatric conditions (excitement, violence, vandalism, roaming, etc.), the following responses were given by sanatoria. One sanatorium requested help from a hospital with a psychiatric ward, four sanatoria used manpower such as the caretaking staff of the sanatoria, one sanatoria got help from the patient's family, and three responded that sometimes they used restraints.

As for requests from those as psychiatrists working at sanatoria, they listed such things as "an increase in the number of psychological counselors and psychiatric therapists" and "clarification of how to handle cases falling under medical protection hospitalization (by the Ministry of Health, Labour and Welfare or the sanatorium self-governing association).

4. Survey of Psychiatric Prescriptions at Sanatoria for Hansen's Disease

To estimate the rate of psychiatric disorders at sanatoria for Hansen's disease, we surveyed prescriptions for psychiatric medicines.

The subjects were 465 residents at Nagashima Aisei En whose prescriptions are all available. As of July 27, 2004, their average age is 77.0 years. With the help of the pharmacy department, we obtained the number of patients taking a psychiatric medicine as of the same date and studied the contents of the medicines.

256 of the residents, or 55.1%, were taking prescription psychiatric drugs. The breakdown according to type is as follows: 40.0%, the largest proportion, was sleeping pills, followed by anti-phobia pills, which made up 25.4%.

By combinations of psychiatric drugs, we classified the patients into several groups: "excitement/behavioral problem group," "depression group," "seizure group," "sleeplessness group," and "phobia/nervousness group." The percentages were 7.5% of the residents in the excitement/behavioral problem group; 4.3% in the depression group; 2.2% in the seizure group; 24.1% in the sleeplessness group; and 17.0% in the phobia/nervousness group.

This survey found that 7.5% of the residents were having excitement/behavioral problems, which was significantly lower than 8.5%, the combined rate of schizophrenia and senile dementia among Japanese of the same age group. The rate for the depression group was 4.3%, which is within the range over the entire country (4 to 7%), but it was significantly higher than the corresponding rate (3.0%) among Japanese whose age are 77.0 years, which is the average age of the survey subjects. The seizure group rate, 2.2%, was much greater than the endogenous seizure rate (of Japanese). The rate for the phobia/nervousness group, 17.0%, did not significantly differ from the corresponding nerve-related disorder rate among Japanese, which is 5 to 30%. The rate of 24.1% for the sleeplessness group was far higher than the corresponding rate of 7.8%, the percentage of Japanese at least 70 years of age using a sleeping pill.

5. Conclusion

The living satisfaction index scores among the residents of sanatoria for Hansen's disease are generally lower than those of the average senior citizens in Japan, and the percentages of residents being treated for depression, seizures, and sleeplessness are high.

As the residents of sanatoria for Hansen's disease age, the incidence of senile dementia is on the rise, sometimes requiring behavior restrictions. However, such restrictions based on the Mental Health Welfare Law are not allowed in sanatoria, so clarifying procedures for them to be admitted to a psychiatric hospital is necessary.

Compared to senior citizens of the Japanese general public, the percentage of those taking prescribed psychiatric medicines is higher in sanatoria for Hansen's disease. A large percentage of these medicines are believed to be prescribed by doctors other than psychiatrists.

D. Comparative Legal History of Treatment for Patients of Hansen's Disease and Psychiatric Patients

1. Common Element: Policy Initiated to Protect Government Reputation

Let us first compare and analyze the changes in treatment for Hansen's disease and the changes in policies for patients of mental disorders.

These policies have a common element: they were initiated, not for the purpose of rescuing the patients from their suffering, but for protecting the external image and maintaining the national reputation toward other countries. The Mental Health Law, first established under the occupation, has been revised for external considerations each time after certain incidents such as the stabbing incident against Ambassador Reischauer and the Utsunomiya Hospital incident. However, often the government lacks a sincere attitude to seriously accept criticisms of other countries, resulting in ignoring it or simply attempting to fix the surface to appear good. Ignoring international opinions was quite evident in the process of revising the Leprosy Prevention Law.

The first reason for ignoring international opinions in the medical treatment of Hansen's disease was the belief that "leprosy is incurable," held by Kensuke Mitsuda, the central figure in the medical field regarding Hansen's disease in Japan. All of the leadership of sanatoria for Hansen's disease and of related scholarly societies were filled with members of his school or clan. The government administration did not have any attitude to criticize that. In the area of medical treatment of mental illnesses, some leading psychiatric scholars believed the myth that schizophrenia cannot be cured, and there were government bureaucrats of the Ministry of Health and Welfare who used to get a large piece of the budget by stressing the danger of patients with mental disabilities. To those who managed private psychiatric hospitals, on whose shoulders most of the medical treatment of hospitalized psychiatric patients fell, day-to-day management and maintenance of their hospitals was far more important than studying the trends of other countries.

2. Public and National Sanatoria for Hansen's Disease vs. Private Psychiatric Treatment

However, there is a sharp contrast: whereas most of the treatment for Hansen's disease was done by the government and municipal public entities, measures on psychiatric disorders, particularly their medical treatment, was largely left in the hands of private entities. Here, let us take a quick look at tuberculosis. More than 100,000 people had died annually of tuberculosis beginning in the 1910s, but the Japanese government did not seriously deal with tuberculosis until 1937, when tuberculosis had a serious impact on and threatened the replacement of (filler) soldiers in the military. In other words, the characteristic pattern that the government had shown was that it would not seriously deal with an issue unless and until it becomes crucial to a national policy, even if the issue is a severe illness or disease to the people. Hansen's disease is an infectious disease, requiring some government policy. However, the capitalist structure did not work well to address the issue, so private specialized hospitals and sanatoria for this disease hardly developed well. Besides, there were not too many patients. This is probably what led to the public operation of the treatment for Hansen's disease. On the other hand, the number of psychiatric patients was rather large, and private psychiatric hospitals were gradually being developed. Perhaps the government, in desperate financial conditions, determined that it would like to cut the budget for psychiatric patients as much as possible. Further, particularly stressed was the "divine compassion" of the imperial family toward patients of Hansen's disease while the same toward patients of psychiatric disorders was rarely shown.

3. Government Policies That Did Not Change Even After the New Post-War Medicine

For Hansen's disease and mental illnesses, introduction of new drugs after the war was truly revolutionary. However, medicines like Promin did not influence the revision of the Leprosy Prevention Law. The Mental Health Law had been enacted prior to the introduction of new psychiatric drugs. As this law was administrated focusing on compulsory hospitalization of patients even after the psychiatric drugs were used popularly, the law did much to inscribe the impression in depth upon people that patients with psychiatric disorders were dangerous. Behind the fact that the revolutionary, new drugs did not lead to policy changes, both on Hansen's disease and mental illnesses, was the delusive conviction of the doctors that fundamentally neither of these are curable. Furthermore, it was related to the outdated attitude of Japan's medical theory that could not shift to the dynamic concept of cure and healing. Medical treatment was extremely poor in quality, both at treatment facilities for Hansen's disease and at psychiatric hospitals. Here is another point in common: at treatment facilities for Hansen's disease, the residents were assigned to take nursing care of other patients; even today, it is considered that fewer doctors and nurses are needed at psychiatric hospitals than at general hospitals. These are almost identical situations. In both cases, there was emphasis on segregation and confinement rather than on medical treatment. Both were monotechnic department of closed-room type environments which were cut off from the general public, and internally special authority relationships existed. In both cases, at some stage there were excess institutionalization was carried out (in terms of the numbers of people living in confinement), further lowering the quality of treatment, which had been already very low.

4. Treatment Stipends and General-Supply Stipends Significantly Cut

Treatment stipends and general-supply stipends were more significantly cut than at general hospitals. In particular, the treatment stipends at treatment facilities for Hansen's disease were less further than the general-supply stipends at psychiatric hospitals. How, and on what ground, and through what kind of review process, were such discriminatory policies made? These are some of the questions that need to be pursued in the future.

5. Devastating Damage by the Eugenic Protection Law

The Eugenic Protection Law, a "revised" version of the Citizen's Eugenic Law, did much damage to both Hansen's disease patients and psychiatric patients. The facts that these patients were robbed of their right to a fair trial and were falsely accused of crimes deeply speak of the severity of discrimination against diseases in Japan. Namely, that was the Fujimoto case of 1951 in relation to Hansen's disease, while that was such cases as the Shimada case of 1954 and the Noda case of 1979, in relation to patients with mental disorders. Masao Akahori, who had been sentenced to death in the Shimada case, was eventually acquitted in a retrial in 1989.

What's more important is that these things all occurred under the new Constitution of Japan, which went into effect in 1947. It is quite natural that in 2001 The Kumamoto District Court found the Japanese policy on Hansen's disease unconstitutional in the Hansen's Disease Government Liability Lawsuit. Necessarily a similar movement will develop with respect to the Japanese policy on patients with psychiatric disorders, including the Medical Treatment Observation Law for the Mentally Incompetent Persons.

6. Patients' Campaigns

In the lawsuit-related process leading to Kumamoto Court's decision, campaigns by patients were significant. In contrast, on the side of people with psychiatric disorders, while there is a nationwide family support group, campaigns by patients themselves are quite small, with some opposition within. The Japanese Association of Psychiatric Hospitals, which includes almost every private psychiatric hospital, became a powerful promoting force in the enactment of the Medical Treatment Observation Law for the Mentally Incompetent Persons. Some leading figures appear both in the history of Hansen's disease treatment and of mental illness treatment, including Shoji Yamane (politician and physician) and Shigenobu Ohkuma in the early period, Sazo Ujihara (engineer in the Ministry of the Interior, a physician) in the middle period, and Fujio Ohtani in recent days.

7. What Segregation/Confinement Did to Patients

What did the segregation/confinement forced upon patients of Hansen's disease and psychiatric patients do? Hospitalization forms and treatment of psychiatric patients vary significantly over time, so here we consider the compulsory hospitalization of patients by legal control, which has been the most popular hospitalization form after the war. Originally, compulsory hospitalization by legal control was supposed to be for a short period of time, but it was implemented like social security prior to the full implementation of the (national) health insurance system. It was not rare that patients or their families requested such hospitalization. Eventually the number of long-term patients (forcibly) hospitalized by legal control has grown, and even today some patients have been hospitalized for 20 or 30 years in the form of compulsory hospitalization. All hospitalized psychiatric patients, not just those (forcibly) hospitalized by legal control, have been under very strict limitations concerning interaction and communication with those outside the hospitals. It is still this way today. At sanatoria for Hansen's disease, the general rule was lifetime stay. In both cases, patients were cut off from the society and have lost a place to return to even if they recovered.

8. What the Society in General Gained and Lost

What did the general public gain by such segregation of patients? Perhaps they gained a sense of relief by removing "odd, strange" people from among them and taking them far away from the society. However, the segregation of patients of Hansen's disease did nothing to reduce the rate of incidence of the disease. The rate went down for other reasons. Compulsory hospitalization by legal control of those psychiatric patients who show symptom that could cause harm to others may have been helpful in preventing such harm of that situation; however, in a vast majority of the cases, a symptom that could harm someone else lasts only for a short period of time. There was no reason whatever for keeping such patients in confinement for a long time. In general, the "policy on patients with mental disorders" is not directly linked to crime prevention. The government and municipal public bodies have spent an enormous amount of public money to maintain such a false sense of security. Further, long-term segregation and confinement of patients of Hansen's disease and mental illnesses have strengthened the prejudice against these patients among the people, stereotyped it, and furthered discrimination. Such prejudice and discrimination then prevented early consultation and diagnosis of mental illnesses because patients often would not want to visit a psychiatric hospital known around the neighborhood. When a renovation project of a psychiatric hospital or new construction of a facility that helps patients return to the society was proposed, huge opposition took place with reasons such as "our children's safety will be threatened" or "the real estate market value will go down," then these projects and construction were cancelled. And even today these things occur so often that we couldn't even enumerate those. In Japan today, there is prejudice even against visiting a psychiatric clinic, let alone being hospitalized in a psychiatric hospital.

Exclusion of patients of Hansen's disease and psychiatric patients did create a hallucination of health and peace, perhaps. At the same time, the society lost patience and compassion toward the weak and the sick among them as well as willingness to walk slowly with them. Modern psychiatry has been discovering new disorders like personality disorders, various dependencies, advanced autism, etc. Infectious diseases like AIDS have appeared, and there are more risks that new infectious diseases are likely to appear. More certain is the aging of the population, which will inevitably produce more weak and sick people. When one loses patience and compassion, ironically the same person will more likely be an object of prejudice and discrimination.

How can we have the patients of Hansen's disease and psychiatric patients gain back what they have lost? This is a very big challenge facing Japan today.

18. Roles and Responsibilities of the Medical and Clinical Community #11

A. Responsibilities of Medical and Clinical Community

The policy on Hansen's disease in Japan can be roughly divided into three periods, and each period had expert-leaders.

The first period was from 1907 to 1953, the period characterized by the establishment, and the powerful promoting, of the absolute segregation policy, when the first generation of experts represented by Kensuke Mitsuda played an active role. The second period is from 1953 to 1996, a period of some 44 years. This is the period in which the concept of the segregation policy was not abandoned despite the fact that it became known that chemotherapy made such segregation unnecessary. A second generation of experts was active then. The third period is from 1996 to now, and a third generation of experts is active.

The first generation of experts caused huge damage to patients and families alike by spreading and infiltrating among the people the erroneous message, rooted deeply in prejudice against Hansen's disease, in order to achieve the absolute segregation policy, that the disease were a strong and incurable infectious disease caused by an extremely toxic bacillus, and that this were a special disease that must be exterminated immediately, no matter what the sacrifice may be. In order to shut up patients in sanatoria for life, they encouraged marriages within sanatoria and imposed at the same time sterilization by vasectomy and abortions. This medical expertise on Hansen's disease was totally unscientific and filled with logical inconsistencies, far removed from international common sense. But they believed that the Japanese absolute segregation policy is the only correct policy on Hansen's disease and even attempted to spread it worldwide. The experts in this period should also be held responsible for directly and systematically working on the government policy to promote the absolute segregation policy.

The responsibility of the second generation experts is just as serious as that of the first generation. Their medical expertise on Hansen's disease followed that of the first generation of experts in that it was also unscientific and filled with logical inconsistencies, but their biggest and most serious fault was that they did not pressure the government to abandon the absolute segregation policy, even while they were in a position to know the fact that the world has completely abandoned the isolation policy as preventive measures due to the spread of chemotherapy. If Japan would have learned from other nations in abandoning absolute isolation in the 1960s, integrating medical treatment of Hansen's disease in general medical service, and encouraging the patients to return to the society, this unbelievable abnormality we see today, unprecedented in the world, could have been avoided. In this regard, the seriousness of the responsibility of these experts cannot be doubted by any means. They taught an erroneous theory that any patient who test positive in the slit skin smear test can be a source of infection of Hansen's disease, stressed that the (New) Leprosy Prevention Law should be kept under the category of infectious disease prevention laws, thus delaying the repeal of the Prevention Law and enlarging the damage.

The third generation of experts did not directly get involved in mandatory isolation; they are treating those in sanatoria as the victims of the erroneous policy of the first two generations. Their prejudice against Hansen's disease is relatively small, but their expertise in the medical knowledge of Hansen's disease, particularly epidemiology, somatic constitutional heredity, and molecular biology related to Hansen's disease, is insufficient. They are, therefore, not sufficiently meeting the expectation of the people, who want to popularize the correct pathological theory of Hansen's disease to the general public through educational activities. Some of these "experts," lagging behind in the modern medicine regarding Hansen's disease that advances every day, are teaching the old-fashioned erroneous theory of Hansen's disease to the public, misinforming the people concerning Hansen's disease.

Due to the decreased number of new patients of Hansen's disease in this country, more physicians in general hospitals, without any diagnostic experience with Hansen's disease, are treating these patients. To alleviate this disadvantage to the patient coming from the lack of experience of doctors, expert doctors with experience of Hansen's disease therapy have established a support network. However, there is no mechanism to assess the propriety of these support physicians, so it is possible that improper advice is given from time to time. It is thus necessary to construct an assessment system that the Japan Leprosy Association can be responsible for and recommend.

Summarizing the observations above, the medical studies concerning Hansen's disease in this country turned its back on patients and their families for the sake of the absolute segregation policy; it was reduced to nothing but a tool in the hand of the government administration that could present a makeshift theory without shame or guilt. In the midst of this, the fault committed by these experts is that they brought about an irreversible tragedy by re-creating and enhancing prejudice and discrimination against Hansen's disease (that had been in Japanese society since ancient times) by popularizing a medically erroneous view on Hansen's disease instead of eliminating them by scientific knowledge produced by modern progress in medical science. Patients and families ended up suffering double discrimination and persecution. The government, meanwhile, did nothing about the discrimination against this disease as being an infectious disease or the discrimination against the family as having bad genes.

The Japanese-style absolute segregation policy on Hansen's disease isolated the medicine and medical practice of Hansen's disease themselves from other branches of medicine and medical practice. As time goes on, the distortion caused by the isolation is being corrected gradually, but even now in the third generation, the impact of the isolation policy is present as a deep wound. The experts have an important role to play toward correct understanding of Hansen's disease.

B. Recommendations Drawn from the Painful Errors of the Past

In the past, we the people were deceived by the false advertisement by our own government and by the "experts," promoting such ideas as the absolute isolation and extermination policy on Hansen's disease and Leprosy-Free Prefecture Campaigns, leading to unprecedented damage and tragedy to the patients and their families. From these irreversible, painfully awful errors, we can draw the following four lessons. It is a tremendous responsibility not only for the government and experts but also for us, each one of us, not to waste these lessons or take them lightly. We owe this to patients and their families.

First, it must be widely understood that the only way to guarantee the human rights of patients of infectious diseases and to prevent the spread of the infection is to provide the best possible medical treatment to the patients, not their isolation or extermination. For an acute infectious disease, it may be necessary to have mandatory isolation, but the limitations on the human rights of the patient in such cases shall be absolutely minimal, and the best medical treatment must be guaranteed to the patient. Because chronic infectious diseases are not as contagious as acute infectious diseases, and because isolation is impossible without seriously violating the basic human rights of the patients, in general the patients shall not be isolated.

Second, the medical science and the clinical community shall work diligently to establish medicine and medical practice from the standpoint of patients and their families as well as to develop and enhance such a mechanism and/or system as to secure this goal. What is pointed out by the erroneous absolute isolation policy on Hansen's disease in Japan is that the medical and clinical community, who promoted and did their share to implement this policy, completely lacked a viewpoint of the patients and their families.

Third, such a legal system and the like shall be developed as to establish "patients' rights" including informed consent and second opinion, etc. so that patients and their families would not have to blindly submit to authorities of the government and experts but instead would be able to decide for themselves which theory is correct.

Fourth, the government and the society shall unceasingly work to create a society that is friendly toward all who are sick or disabled.

19. Roles and Responsibilities of the Legal Community #12 (_1)

A. Purport of the Verification

Was it that one of the main reasons for the extreme delay in the repeal of the Leprosy Prevention Law of 1953 was as follows?: while some records remain concerning sincere efforts of a few legal experts and organizations for individual cases, overall legal experts and organizations did not fulfill the responsibilities entrusted by the society and did not take necessary actions. Based on this hypothesis, we verified responses and responsibilities of legal experts and organizations of Japan toward the repeal and/or revision of leprosy-related laws, centered on the Leprosy Prevention Law, with a special focus on the period after May 3, 1947, when the new Constitution went into effect.

B. Legal Situations Prior to the War

Prior to the war, criticizing of legislation was difficult. This is because, under the former Imperial Constitution, "the right to establish laws belongs to the prerogative of the Emperor." In political theory, "democratic imperialism" was proposed as a revisionist democracy by Sakuzo Yoshino, but its focus was "for the people," clearly distinguished from democracy ("of the people, by the people") wherein the power belongs to the people.

C. Actions of Lawyers' Organizations and Individual Lawyers

In the patient abuse case in the heavy-security cells "special wards" at Rakusen En, the Japan Lawyers Association for Freedom brought a charge of murder, etc. (on behalf of the victims and as the third party) to the Maebashi District Public Prosecutors Office. Lawyer Shinkichi Umino of the Japan Civil Liberties Union, involved in the Battle against the establishment of the Leprosy Prevention Law, listed his name among the founders of the "Association to Protect the Rights of Leprosy Patients." Lawyer Masaji Nojiri, et. al. of the Japan Lawyers Association for Freedom defended Fujimoto in the Fujimoto case, and another lawyer who worked in the same case, Isamu Sekihara, gave lectures to sanatorium residents concerning some fundamental issues related to patient labor in the Miyashita case.

The Government Liability Lawsuits on the unconstitutionality of the (New) Leprosy Prevention Law was carried out with lawyer Yasuyuki Tokuda, *et al*. at the Kumamoto District Court brought in July, 1998; with lawyer Makoto Toyoda, *et al.* at the Tokyo District Court brought in March, 1999; and with lawyer Akio Hirai, *et. al.* brought in September, 1999, as plaintiff's attorneys.

D. Actions of the Bar Associations

At the Tokyo Bar Association, the lawyer's association covering the location of Tama Zensho En, lawyer Yoshio Watanabe of the Medical Problem Research Group under the Human Rights Protection Committee raised an issue about the current reality of clinical treatment and had a discussion with the All-Japan National Leprosaria Patients' Association in 1977. Lawyer Masayasu Yamada raised an issue concerning the eugenic protection concept and medical practice in 1986; however, there is no record showing any other activities held open to the outside the association in a relatively early stage.

Even at the Japan Federation of Bar Associations, a study by the Group on Medical Issues under the Human Rights Protection Committee did not begin until 1994, and it was not until 1996 when the chairman of the federation issued a statement and his opinion concerning the "Revision and Repeal of the (New) Leprosy Prevention Laws." Indeed, it was too late. Studies by the Group on Medical Issues of the Human Rights Protection Committee concerning various problems that arose after the repeal of the (New) Leprosy Prevention Law were also processed with much delay due to insufficient organizational responses.

E. Actions of the Courts, the Public Prosecutor's Office, and the Ministry of Justice

Around 1952 to 1972, police boxes (special and dedicated boxes) were built. Since 1954, jails (special and dedicated jails) were built. From 1947 to 1972, extension court trials (designation of sites for holding trials besides the courts) were held, and between 1953 and 1997, Kikuchi Medical Prison Branch (special, dedicated prison) was founded. These, however, should have raised questions like "Would this lead to more discrimination?" "Would this not violate equality under the law?" "Would it not violate the right to a fair trial?" "Would it not violate openness of court trials?" and "Is the phrase 'when deemed necessary' found in Sec. 2, Article 69 of the Court Law of the Supreme Court not misinterpreted?"

F. Actions of the Law Study Community

In the community of law scholars, even on an individual researcher's level, no one actually questioned the government interpretation that the (New) Leprosy Prevention Law was constitutional. Neither was there any theoretical review concerning revising the (New) Leprosy Prevention Law from the standpoint of unconstitutionality.

Studying the comments of legal experts, it appears that, in the theory of constitution, the accepted notion that the basic human rights could be limited in general if required by "public welfare" were in support of leprosy prevention law system, with some judicial precedents in line with that notion Among theories against the notion is the theory (by Toshiyosi Miyazawa) that considers it ("public welfare") to be the principle of substantial fairness as a principle that adjusts inconsistency clashes among the various human rights. From the standpoint of this theory, a question should be raised of whether or not general benefits that are protected even though strictly they are not rights (such as the benefit of being protected from infectious diseases) can be strictly called human rights; then, the freedom of residence and relocation of patients of infectious diseases and those who may be infected cannot be limited by reason of public welfare.

Also, there are three principles in the theory of relationships among special authorities: (i) the agency with special authority is given power to comprehensively rule others, including the power to give orders and the power to penalize someone, thus able to rule comprehensively those within the relationship on an individual basis without legal ground; (ii) the agency with special authority can limit, without legal ground, the rights and freedom of a citizen subject to the agency even if the rights are guaranteed to each citizen; and (iii) since the acts of the agency with special authority on those who are subject to the agency are exercises of the power to rule, judicial review are excluded as a rule. Apparently, they all directly supported the leprosy law system.

In the theory of administrative laws, the distinction between direct restraint and immediate restraint is unclear; in reality, they sometimes overlap. In implementing administrative compulsory execution including direct restraint, there used to be the Administrative Execution Law as a general rule before the war. After the war, this law was reviewed with the criticism that it was likely to violate human rights, so the Administrative Execution Law was repealed, and instead the Administrative Subrogation Law was enacted, under which direct restraint was allowed as exceptions by individual laws. "There exists no general law concerning the obligation to act with non-alternative or enforcement of the obligation to act; only individual laws stipulate such obligation where necessary (… as for direct restraint,… Article 6 of the (New) Leprosy Prevention Law, etc.)" says a comment by Tsuyoshi Kodaka.

G. Delay of Actions by the Legal Community

Such as the occupational ailments of legal experts include ignorance of topics outside their specialized area and cowardice, limitation of legal practice by individual lawyers and of public-interest activities by lawyers associations, and lack of actions to be taken by them against the establishment of the 1953 Leprosy Prevention Law, these facts suggest that, throughout the process, the legal community consistently maintained the attitude that "no see, no hear, no say." Such a delay of actions for revising or repealing the (New) Leprosy Prevention Law is absolutely inexcusable.

H. Recommendations for the Future

We desire that efforts should be made to inoculate legal experts from their occupational ailments, to polish and enhance the activeness of legal experts, to systematize their problem-awareness, to reform bar associations, and to reform their training in law and in human rights.

As for individual legislation, it is necessary to re-examine for narrow interpretation of the concept of public welfare, which became the basis for implementing compulsory enforcement under infectious disease legislation, to establish basic principles for laws related to infectious diseases, and to clarify, in a general law, the limitations on administrative immediate restraint.

20. Roles and Responsibilities of the Welfare Community #12 (_2)

A. Extent of Verification and Challenges

Taking into account the record of practice and research history of public and private projects carried out under names such as charity projects, social projects, and social welfare, and keeping in mind the characteristics of each period, we comprehensively studied as an object of the verification how projects were carried out for patients of Hansen's disease and their families, especially how they were related to the history of formation and development of the segregation policy on Hansen's disease. Further, we also examined the process that actually increased further the pains and sufferings of residents of sanatoria, because, under the segregation policy, all of the activities in medical treatment, research, and welfare for Hansen's disease were managed apart from general policies like living protection, children's protection, and support of returning to the society, and they were put outside of the mainstream of such projects and activities under the principle of complete segregation.

B. Public health and social work, particularly poverty aids and medical assistance to the poor, were both established with such characteristics as being heavily tinged with public security policy and measures. These were both developed by a common group of leaders who went abroad to study systems of other countries and modified their systems to suit the Japanese society. These were developed with the purpose to maintain the reputation as a modern nation; both of them were under jurisdiction of the Ministry of the Interior. Hence, from the beginning period of the segregation policy, the social work community fully agreed with the segregation policy taught fervently by Kensuke Mitsuda. Prior to this, aids and support had been provided to people and villages that had been extremely poor due to Hansen's disease, mainly by Christian missionaries from overseas under the name of charity projects. However, they were then organized as "correctional rescue projects" under the selection and organization process through the funds given by the imperial family. With this shift, the practical power to criticize the government policy was lost, and modern voluntary projects were weakened. Consequently, quite easily, these projects and works were merged into the flow of building sanatoria for Hansen's disease and sending patients to confinement there. Private hospitals including those managed by foreign nationals were suffering from extreme management difficulties. There was at the time an opinion in the social work community that medical practice as projects of modern medicine should be unconditionally trusted to the medical experts, hoping that the result would be at least better than the low quality of charity projects. In that sense, the low standard of welfare and the poor level of public welfare ended up hiding the problem of the inferior living standard of sanatoria, thus indirectly contributing to the continuation of the low quality.

The welfare community depended on the segregation policy, hiding behind it, and they were not sufficiently aware of the seriousness of the problem as they beautified the people who worked there.

C. Those in the welfare community who had been involved in charity projects for Hansen's disease were most concerned from the beginning with the holistic protection and guarantee of the living conditions. Specifically, they were concerned with the raising and educating of children who were born of parents with the disease and those children left behind by parents who could no longer raise them due to the disease. Under the pretense of modern medicine or by an emphasis on the infectiousness, parents were removed to the world of "medical treatment," leaving behind their children. Rearing of these children, support and protection of the remaining family members, and care-taking of elderly parents became new challenges in the welfare community. The community got involved somewhat, including child-rearing (via delegation) directly in sanatoria and providing human resources. However, these were very limited efforts from the perspective of their influence on the welfare community as a whole.

D. During the progress of the segregation policy, symbolized by the increase to 10,000 beds and Leprosy-Free Prefecture Campaigns, obtaining funds in the midst of the Showa turmoil was a difficult task. In the period when construction was difficult because of the expansion of the military budget, what supported the funding was the existence of social workers throughout the country (established by law when the Aid Law went into effect) and, financially, Mitsui Ho-On Kai, an organization that assist social projects. In our verification, we analyze these two in particular-the historical background of their founding and the characteristics of their organization, clarifying their link to the segregation policy.

E. Meanwhile, as for the conditions of "family support" mentioned earlier, the welfare community could not achieve the intended objective; the reality was that they were not able to earn trust from residents of sanatoria. There are several reasons for this. First, despite the fact that this had been a critical challenge to individual private projects earlier, no measures were taken in early stages of sanatoria; instead, everything was entrusted to the sanatoria. From the standpoint of the main purpose of the Prevention Law, this was actually an extra task to be done on the side, so it had to be organized as a project of the Leprosy Prevention Association. Further, residents of sanatoria did not want to disclose their home and often used aliases in the fear that their family members would suffer. They did not even want to communicate with their home city, town, or village. The intended projects would have involved daycare centers for small children, living assistance to families, and senior citizens' homes. The welfare community sometimes provided regional models and sometimes sent veteran staff members. But their assistance was limited to these from the outside. Although there were a few researchers who discussed these issues theoretically, the welfare community as a whole had extremely partial involvement.

F. After the war, the welfare community was given another opportunity to stand at an intersection of Hansen's disease and the society, even under the complete segregation policy that had not changed at all in general. New chemotherapy, led by Promin, allowed patients to be more stable and improved, giving them hope that they could return to the society. There was a time when a large number of patients left sanatoria, followed by a stagnation period. During that time, along with discussions to re-organize sanatoria, case workers (post-war jobs dedicated to social welfare) and various facilities for the physically disabled were introduced to the society, giving multi-faceted expectations. However, due to the segregation policy, these were not situated among the intended tasks of sanatoria. Consequently, the problem of standards for leaving the sanatoria, the problem of health maintenance after leaving the sanatoria, job raining, financial security of those who leave the sanatoria, lump-sum payment, communication with the family, handling of assets, and other counseling topics were all handled in a very fragmented way, without any understanding of the feelings of the residents. These factors and the damage due to them are described (in the Final Report).

G. Even surgical rehabilitation, already a normal practice internationally, was also carried out as a fragmented measure; it was implemented without the image of rehabilitation to be had by an entire sanatorium as a whole, so each medical and clinical technology were introduced randomly, only to be evaluated within each process. Hence, the awareness of the need for social and psychological rehabilitation, systematic teamwork, and assessment and support methods for social rehabilitation all varied from sanatorium to sanatorium; the levels of case workers, as well as their assistance methods, also varied widely.

H. In particular, there was no standard for being able to be discharged from sanatoria. The decision was made by the medical department of each sanatorium or a committee of discharge standards. During some periods, some sanatoria had many "accidental discharges" of those who were not officially permitted to leave. Those who left sanatoria without accurate evaluation, with insufficient education, had no skills or power to earn money. They were without social security or protection and had no choice but to struggle and suffer. In addition, if the sickness reoccurs or the condition gets worse, there was no way for them to be treated without going to a sanatorium. These contradictions were discussed and made known throughout the 1960s history among experts and even patients themselves through scholarly symposia and journals at various sanatoria, but nothing changed. Despite the desires of individual clinical health-workers, accurate follow-ups did not materialize. The useful and practical experience of a few innovative "pioneers" who worked hard with motivation and diligence was not actively utilized for those who later left sanatoria.

I. In sanatoria, most of the patient labor was being replaced by hired staff members, but the mental and physical load of those who worked on the management and maintenance, including self-governing association activities, actually increased. Many of them could not leave their sanatorium friends behind, and there were also those who had decided to stay at sanatoria. Some of them had not communicated with family for years; some had sequelae because the new drug became available too late for them; and yet others had difficulties returning to the society due to the disease or due to the lack of leads. There was a deep psychological gap between these patients and those who wanted to return to the society. Therefore, the complete segregation policy, unscientific and non-realistic, caused damage and complicated it further, equally to those who decided to leave and actually did so, and to those who decided to stay at sanatoria.

J. It could be said that it was not until the 1980s that the cooperation between clinical medicine and welfare was seriously considered. Experts of clinical welfare were "junior" specialized personnel at the clinical front; they were few in number, and their capabilities were, in reality, far short of the ideal. The welfare community has many challenges for the future in regard to Hansen's disease. This is the time to learn from these lessons from history.

21. Roles and Responsibilities of the Educational Community #13 (_1)

A. Effects on Children and Education

How did Japan's policy on Hansen's disease affect children and the field of education? Under the Japanese Constitution and the Basic Law on Education, all children were guaranteed the right to learn without educational discrimination. From the perspective of children's welfare, guarantee of children's learning and living was promoted. Under the "(New) Leprosy Prevention Law," it was stipulated that teachers be sent to patients in sanatoria to maintain the principle of education guarantee. However, the reality surrounding the children was far different, and education guarantee proved to be extremely difficult. Under the compulsory segregation policy, the survival and human rights of children were constantly in danger by discrimination and prejudice seen in such phenomena as family separation and refusal to "co-education".

B. Reality of "Education" in Sanatoria for Hansen's Disease

"Education" in sanatoria can be divided into three major periods. During the private tutorial ("terakoya," or "temple school") period, a "patient-teacher" taught children on a "private" basis as in a temple school. The second period, the school education period, was when a "structure like a school" was being organized in the midst of the "Leprosy-Free Prefecture Campaigns," which increased the number of confined patients drastically. The third period, the branch school and branch classroom education period, established schools as branch campuses of local public schools. However, "those who are assigned the task of teaching in mandatory education in sanatoria are grossly incompetent" (from *Fundamental Measures for Leprosy*), and further extension of the facilities was sought. In addition, there was no budget for educational supplies, etc., so they were obtained from overall general supplies (of the sanatorium). "Neither the government nor the facilities had any real intention of providing normal education to children in sanatoria, and courses in specialized areas cannot even be hoped for." Only in the 1950s, the costs of education supplies were included in the budget. It was a very difficult educational environment to implement mandatory education in a meaningful way. Educational facilities for children with Hansen's disease completed its role when Niirada School was closed in 1987.

Now, what type of person did they try to train through education? For instance, at Nagashima Aisei En, the goal was "to be a good Aisei En resident" and to "accept the system of the sanatorium and live your treatment life submissively here in." It was so that children can "read the newspaper, write letters, and calculate the sanatorium-only currency." In other words, education was a tool for living there, and "aptitude" meant "aptitude to live in the sanatorium." This was the other side of the coin called segregation, or "closed aptitude." Of course, the experience of being pulled away from family and home impacted the formation of the children's senses and personality significantly. Compulsory segregation forcefully robbed the children of the "foundation for security" and deeply hurt their hearts.

As for "children who were yet uninfected," "often they were denied education by relatives as well as by various children's facilities of prefectures." There were many difficulties if they were to try to be admitted to general educational facilities. Going to school was not easy, either; at Nagashima Aisei En, neighbors raised an opposition when the children at the child-care center in the sanatorium were to go to school. As there was no sufficient measure to promote correct understanding of Hansen's disease in local communities, ideas based on discrimination and prejudice was preserved, eventually stripping the children of their right to learn and even the equality for educational opportunities. For those children themselves, just on account of "leprosy," they had no choice but to feel deeply the weight of the meaning that this disease had, and it had devastating effects on the psychological life of the children.

C. Founding of High Schools and Return to the Society

Going to the high school (Niirada School at Nagashima Aisei En) was a means by which the resident patients could become "complete persons." Entering the high school for educational training meant, to each student, obtaining the guarantee of their right to education and the right to learn. At the same time, it had another significant meaning as the educational experience would lead to their return to the society. Going to the high school was a first step to escape from the isolated society.

However, entering the high school turned out to be "to be reminded of the fact that they are patients." The memory engraved in their hearts was nothing but humiliating experiences because of Hansen's disease. After entering the high school, "the sense of inferiority was constantly and unconsciously planted" in such situations as school trips and the problem of "bell system". Meanwhile, however, demanding campaigns by student bodies and campus democracy movements had a huge potential to bring about drastic changes in the conditions into which Hansen's disease patients had been placed, and at the same time, they made it very clear that the government and sanatoria were not actively taking care of the educational conditions in sanatoria.

The fact that the high school were founded as a result of the Battle against the "(New) Leprosy Prevention Law" was quite significant, but problems remained. The All-Japan National Leprosaria Patients' Association wanted three schools to be open, including a regular, daytime high school. These did not materialize. A question still remained as to how "equal" the educational opportunities were. The fact that the educational environment was totally based on discrimination and prejudice was seen in such areas as the use of the "bell system," the requirement to wear white coats, mandatory disinfection, and problems related to school trips. The very notion that the Japanese policy on Hansen's disease had toward the patients of Hansen's disease was used to define the children's classroom space, their right to learn, and even their individual human rights. Even in the 1970s, when the idea of normalization was gaining popularity, segregation to a remote island continued, making it extremely difficult for patients to return to the society. There were problems with finding employment after graduation, also. Some have hidden the past, and others complain of not being able to make true friends. Problems remain to this day.

D. Children's Co-Education Denial Case in Tatsuta Dormitory at Kurokami Elementary School

In 1953, children of Tatsuta Dormitory, who used to be referred to as a "taboo" and "forgotten beings," were denied admission to, and co-education at, a school. It was triggered when Miyazaki, director of Kikuchi Keifu En, appealed to the Kumamoto District Justice Bureau to eliminate the discrimination. The Ministries of Justice, Health and Welfare, and Education got together in a three-ministry conference the following year and concluded that "there is no evidence that leprosy is contagious," "the dormitory children should be allowed to go to general school," and "in childhood, the most crucial period of personality formation, being discriminated against from other children and being denied equal educational opportunities would not be appropriate in a democratic society based on respect of human rights." They then criticized the opposition movement by PTA, stating that it was "denying equal educational opportunities by means of violence of many" and that they "should deeply regret and apologize for" such an action. The opposition, in contrast, decided to corporately cancel school and tried to interfere with children going to school for the opening ceremony. They put up a large poster on the school gate, saying (in children's language and writing) "We will not go to school for a while so we wouldn't have to study with children with leprosy." For residents of the community, the situation was that "if you do not join our opposition, we will not speak to you any more." Along with the political ambitions of the opposition, political pressure and violence led to problem behaviors. In the end, the problem was not solved by debates in the Diet, and the children went to school from the private home of the president of Kumamoto Business College. Eventually, no children of Tatsuta Dormitory that were admitted graduated from Kurokami Elementary School. Tatsuta Dormitory was shut down. This incident was definitely a case wherein children were robbed of their rights to education and learning, based on a preconceived notion founded on discrimination and prejudice against Hansen's disease. The children, who had to give up relations like "family" and "parents and children," were deeply hurt psychologically. The so-called "solution," by leaving the problem unresolved while the government, prefecture, and city did not act responsibly, also contributed to further growth of the unwanted prejudice against patients of Hansen's disease and their children. This can be considered a byproduct of the government's compulsory segregation policy, which helped create the people's biased notion in the first place.

E. Hansen's Disease Problem and the Educational Community

First, concerning a description in a textbook, the All-Japan National Leprosaria Patients' Association protested the description contained in a teacher's manual of a high school textbook of physical education: "Explain that leprosy is a terrifying disease in which leprosy bacteria causes the body to get rot, beginning on the skin." The corresponding content of the textbook was a description based on the "(New) Leprosy Prevention Law," and students were to learn that segregation is the foundation for the policy on Hansen's disease. In textbooks, compulsory segregation had survived. The position of the medical community of Hansen's disease, as the provider of the ground of the description, and the position of the Ministry of Education, as the body that certifies textbooks, should justifiably be questioned.

Next, we address teachers. A student at Niirada School felt that a teacher had "something that is like an invisible wall." Teachers were "foreigners to students." The misconception that Hansen's disease was a powerful infectious disease put limitations on what teachers would say and do. Further, just the assignment of being sent to Nagashima was looked at with prejudice, so the teachers themselves had their own worries and concerns. Good-willed teachers were facing and teaching the children even with some sense of "confusion" and "hesitation." Here we see another big problem created by the policy on Hansen's disease: not only were the children discriminated against, but also educators who were involved in teaching at sanatoria for Hansen's disease became the object of discrimination and prejudice. This caused a feeling of "distortion" not among the children only but also among the teachers.

We now go on to research and achievement concerning the children of Hansen's disease and their education. Currently, many studies are being done in the fields of history of childcare and history of education of disabled children, but they still tend to be considered "special" fields of research. Up to now, problems like the Tatsuta Dormitory incident were hardly ever studied but almost completely forgotten. Research in the field of education will largely depend on the future progress, so in this sense the responsibility of the educational community is significant. It is also desired that educational and informing activities involve historical responsibilities up to now as well.

F. Conclusion

Under the segregation policy on Hansen's disease, Japan's scholarly community of education and the educational community were also "isolated" from the children's right to education and right to learning, not carefully studying the problem. Certain facts are evident from how "education" was handled at sanatoria, the reality of the children's "learning" at the sanatoria, and the problem of violated right to learn by way of denial of co-education. In the educational policy and educational practice toward children related to Hansen's disease, in holding educational and informative events on human rights in the general public, and in the academic discipline of education and educational movements, there was hardly any notion concerning the "children related to Hansen's disease." In other words, the existence of children related to Hansen's disease and their education were almost ignored, overlooked, left behind, and forgotten. This led to a terrible violation of the human rights of those children, spotlighting the gross errors committed by the government and the educational administration. There is no question that these things created discrimination and prejudice against Hansen's disease and the patients, leaving a deep psychological scar in the hearts of the children.

22. Roles and Responsibilities of the Religious Community #13 (_2)

A. As a Resident, As a Religious Person

> "Rejected and segregated, only we who have been discarded have the feeling of 'having given up the world,' as we joined our hearts together to share all joys and sorrows as a fate-sharing community. We with that feeling shall not be blamed for living with a desperate hope of making this isolated island our 'paradise.' Those who put their feet in this land and those who accepted them-all acceded to the segregation as a given, and as something grim. This is a fact that cannot be covered or denied" (Kyosho Ina, *Hansen's Disease, 40 Years of Isolation: Message for Human Liberation*).

This is a message left with a painful emotion by Kyosho Ina (whose alias in sanatorium was Yoshi Fujii) as he faced the last years of his life. He was a resident of Nagashima Aisei En and a Buddhist priest in the Shinshu-Ohtani denomination who dedicated his life (the 48 years of his isolation) to the activities of "Shinshu Friends Association," an organization (in the sanatorium) of the Jodo Shinshu sect of Buddhism.

Ina, who lived "with a desperate hope of making this isolated island" his "'paradise," faced the fact that he and others all simply had acceded to the segregation. Here, we investigate the responsibility of "religion" as we come face to face with the challenge posed by this one resident, who was determined to face the fact.

B. Relationship between Sanatoria for Hansen's Disease and Religious Organizations

About 87.8%, or 3019 out of the 3436 current residents, of the national sanatoria for Hansen's disease are involved in one way or another with a religion or a religious organization in the sanatoria (as of August, 2004). There are close to 90 religious groups in the sanatoria, and religious activities based on religious facilities in those sanatoria have been actively carried out, both before and after the war. Hence, it is not a trivial exercise to study and investigate the influence that religions have had on the residents of the sanatoria for Hansen's disease as well as the damage they have caused in relation with the government policy.

The breakdown of the religious organizations is as follows: Buddhism 48.6%; Christianity 31%; and new religions 8.4%. Compared with the ratios in the general public, one characteristic is the extremely high ratio of the Christian religion.

Among the Buddhist groups associated with sanatoria for Hansen's disease, Jodo Shinshu, Nichirenshu, and Shingonshu are deeply rooted, but particularly Jodo Shinshu and Nichirenshu have played a major role in the continuation of the segregation policy.

"Comforting religious teaching" at sanatoria for Hansen's disease by Jodo Shinshu (especially the Shinshu Ohtani denomination) had begun at the same time when the "Matter concerning the Prevention of Leprosy" went into effect. This was in total agreement with the nation's policy on Hansen's disease.

One particular activity of Nichirenshu was the handling of Hansen's disease by Ryumyo Tsunawaki, who founded Minobu Jinkyou En. Minobu Jinkyou En played a role of the headquarters, so to speak, for all in-sanatorium organizations of Nichirenshu that were yet to be formed in various sanatoria. At one time there was even a branch room in Kyushu. But it was closed in November 1992, with a decrease in the number of residents. As a private sanatorium, it played a significant role in complementing national sanatoria under the government policy.

Christian organizations have also been very actively involved in the Hansen's disease problem.

As mentioned above, over 30% of the sanatorium residents are members of Christianity. This is an enormously large percentage, especially given the general consensus that only about 1% of the Japanese are Christian.

Not many of them were baptized prior to their placement in sanatorium. A majority of them were baptized in their sanatorium and became Christians there and are living their sanatorium life supported by their faith in the Christian religion. This speaks of the powerful influence that faith has on the sanatorium living.

There are a few things to note about the involvement with the Hansen's disease problem by Christian organizations: activities of Kozensha and Japan MTL as support organizations, and the role played by private sanatoria for Hansen's disease founded on Christian doctrine. However, even these were closely connected with the government policy as one can see from the following purpose statement of Japan MTL: "This foundation has as its purpose evangelizing leprosy patients with the gospel of Christ and promoting the prevention and rescue of leprosy with a view to its extermination."

There are also new religions, such as Tenrikyo, that are doing active missions work to residents of sanatoria for Hansen's disease as a religious organization.

C. Role Religions Played in the Continuation of the Segregation Policy

How then have these religious organizations, that were involved in the Hansen's disease problem in these forms, played a role in the continuation of the absolute segregation policy?

> "A national sanatorium for leprosy patients is going to be newly built in the district of Tokyo. We acknowledge the need to shower these patients in the most pitiful conditions in the world with the love and light

> of Buddha and to give them comfort. Its office has contacted our headquarters, and Minister Hasuoka of the Tokyo Yoiku En has voluntarily decided to dedicate himself to this position. This is truly respectable, reminding us of the acts of mercy of Empress Komyo, who rescued many in the Tenpyo (Nara) period" (Religious Bulletin, Shinshu Ohtani Denomination, No. 2, 1910).

This is a short paragraph excerpted from the journal *Religious Bulletin* ("Shuho") of the Ohtani denomination. Here, many key words are listed, showing the religions' role in the segregation policy on Hansen's disease: a call by and response to the government policy, content of "rescue," and harmony with the "imperial compassion."

These are not limited to Jodo Shinshu; in fact, they are commonly seen in all religious organizations involved in the Hansen's disease problem, especially before the war.

Call by and response to the government policy included "promoting public opinions," actively carried out by Komyo Kai of the Shinshu Ohtani denomination, Japan MTL, etc. for the purpose of letting the society and the people recognize, and of entrenching in them, the validity of the government's absolute segregation policy. Many leaflets and posters were created, and religious organizations were used as a medium for the spread of this movement nationwide.

The "comfort religious teaching" for residents of sanatoria for Hansen's disease was also an item strongly requested by the government. The main teaching there was the concept of surrender, giving up. Power of faith was extremely effective in making residents submit to the harsh reality of segregation. Religious leaders responded to this request and promoted the government's segregation policy as a mission for their faith.

Another thing that must not be overlooked in their activities is the connection with the "imperial compassion." Just as the government kept emphasizing the imperial compassion pitying patients of Hansen's disease to promote its segregation policy, religious organizations also emphasized, repeatedly, the imperial compassion along the lines of God's compassion and Buddha's compassion. This may be a crucial factor for things that were taught under the names "comfort religious teaching," and for the contents of "promoting public opinions," to infiltrate through the residents and the general public alike.

Hence, religious leaders' involvement in the Hansen's disease problem was, especially prior to the war, in complete harmony with that of the government.

What then did such religious activities give to residents? In short, was it not a "sense to accept the segregation"?

The residents were in a situation where they had no choice but to humbly bow down to the various humiliating policies; to such people, the idea that living in a sanatorium itself is a form of "salvation" must have shone like light in their lives. The more severe the violation of human rights by segregation was, the more powerfully such "indoctrination" would have been accepted by the residents. The last defensive method when human dignity is violated-it is to cover up the fact that the dignity is being trampled upon. What was used in this cover-up was the "indoctrination" known by terms like "comfort" and "salvation" developed where it was identified with the compassion of the emperor who was transcendent from the world of humans. Covering up the reality of segregation-this, in a sense, may be an extreme form of human rights violation.

D. Why Religious Leaders Could Not See the "Segregation"

After the war, even when the relationship with the government changed drastically from the pre-war period, the nature of the activities of religious organizations in sanatoria for Hansen's disease did not undergo any fundamental changes. They were unable to question the inhumane nature of segregation as a challenge of faith, and instead they continued to teach the residents how to live peacefully within the isolation.

There, a problem is hidden: in the structure of "one that saves" and "one that is saved" taught by religious leaders, religious teaching concludes itself.

Finally, we conclude this section with one proposal toward prevention of recurrence, a lesson which we can learn through our study of the responsibility of "religion" as a factor that contributed to the continuation of our country's segregation policy. We would like to express the following: do not consider the relationship between the religious leaders who enter sanatoria to do missions and the residents who are taught as a relationship between "one that saves" and "one that is saved." Reverse the roles, and build a mutually equal relationship in which humans are helping each other be liberated from that which makes them inhuman.

In the final hearing of the Hansen's Disease Government Liability lawsuit at The Kumamoto District Court, the plaintiffs' attorney team proposed the phrase "from the object of rescue to the subject of liberation." This phrase points to the future direction for religious leaders and religious organizations for the prevention of recurrence.

23. Meaning and Limitation of Patients' Movements (self-governing association movements and the All-Japan National Leprosaria Patients' Association movements) #14 (_1)

A. Constitutional Movement

One can say that the Japanese compulsory segregation policy on Hansen's disease is a structure of "separation" and "discrimination." A wide variety of powers of "separation" and "discrimination" have attacked Hansen's disease patients, former patients, and their families. Among those, the powers of "separation" and "discrimination" from "citizens" have been particularly noted. It goes without saying that the existence of tall walls surrounding national sanatoria has contributed significantly to these powers. On the various "residence damage" suffered by patients who were forcibly isolated into sanatoria, "social damage," centered on "separation" and "discrimination" from "citizens" and removal of social life, was superimposed.

While residents worked diligently to improve the extremely poor life and medical treatment in the sanatoria, even such actions provided momentum which could operate as "separation" and "discrimination" toward the residents, because: "Are we to achieve treatment improvement by submitting to the compulsory segregation? Or should we withdraw our request for treatment improvement in order to eliminate the compulsory segregation policy?"; the government adopted the theory that "compulsory segregation and treatment improvement are the two sides of a coin," which imposed on the residents such an impossible choice. The "separation" and "discrimination" by the government within and without the sanatoria have once again surfaced in the discussion over the pros and cons of the 1996 law to repeal the "(New) Leprosy Prevention Law," and of the filing of the complaint of the Government Liability lawsuit on the unconstitutionality of the "(New) Leprosy Prevention Law."

Against these powers of "separation" and "discrimination" of various sorts that attacked them, the residents worked together to create "unity" and "cooperation" through organizations like sanatorium self-governing associations and the All-Japan National Leprosaria Patients' Association. Despite the much sacrifice they had to make, they fought courageously to seek the kind of living guaranteed by Article 25 of the Constitution and earned many victories themselves. One of their major victories was the court decision of the unconstitutionality of the "(New) Leprosy Prevention Law" on May 11, 2001. To the residents, shut out from the society, standing alone, and having almost no support, the Constitution of Japan was literally the only textbook and a thread of hope. This, however, took a long time.

B. Many Achievements

Looking back at the movements of the All-Japan National Leprosaria Patients' Association, etc., innovative fights have taken place. Beginning with the Battle against the "Leprosy Prevention Law" in 1952 and 1953, they were actively involved in the Children's Co-Education Denial Case in Tatsuta Dormitory (1953 to 55), the rescue movement in the Fujimoto case after he was sentenced to death (August 23, 1957), opposition in the establishment of jails exclusively for patients (1955), a request to the Diet for revision of the Prevention Law and for improving the living conditions in sanatoria (March, 1964), negotiation with the Ministry of Health and Welfare for complete implementation of switching to nurses (June, 1964), actions in the establishment of the basic treatment in the FY1972 budget, the general indignation meeting to improve the medical care in sanatoria (July, 1972), actions to return the managing jobs at sanatoria (July, 1972), efforts for the revision of junior high school physical education textbooks, etc. (1973), initiative to fight again the Battle against the Prevention Law through the *Zenkankyo News* (All-Japan National Leprosaria Patients' Association News) issued on January 15, 1984, actions toward repealing the "(New) Leprosy Prevention Law" on March 27, 1996, and involvement in the Government Liability lawsuits on the unconstitutionality of the "(New) Leprosy Prevention Law," first the West Japan lawsuit was filed in July, 1998. The list goes on. Needless to say, in all these battles, the residents naturally evaluated the role and meaning of the All-Japan National Leprosaria Patients' Association (and others) quite highly.

They have made the following statements: "A movement form where patients as an organization make demands is unprecedented in the world." "The Ministry of Health and Welfare and the sanatoria would have done nothing if the organization had not expressed their opinions on improvement of living conditions and clinical problems. The current living environment and medical treatment are all results of patients' movements, which are to be highly valued." "We have collectively held the notion of human rights as an organization, not as scattered individuals, working hard to achieve happiness materially and emotionally. This is very meaningful, and I feel proud in light of our humanness." "Self-governing associations are history of resistance."

If, however, we pick up individual battles and calmly look at their cross-sections, harsh ideological conflicts surface. Since 1975, influenced by the theory "compulsory segregation and treatment improvement are the two side of a coin," the All-Japan National Leprosaria Patients' Association movements had many inconsistencies and stagnation, to be sure. Measures and actions taken by these organizations concerning the repeal of the Law and the Government Liability lawsuit were not always free of problems. The small role played by women in self-governing association movements will also be seen as problematic. However, when the Law was being repealed, the government had no choice but to promise to maintain the same level of treatment; this is only because the victory of the economic battle had allowed the idea of vesting rights to be rooted deeply within the residents' mind. In this sense, the self-evaluation by the

All-Japan National Leprosaria Patients' Association that the Government Liability lawsuit was a result of the Association's cumulative work does not appear to be off the target. Since the decision of the Kumamoto District Court, such a phenomenon has been seen as the significance of the decision has been shared by many non-plaintiffs, too.

C. Social Support

The history of movements by the All-Japan National Leprosaria Patients' Association, etc. vividly shows that the main body that would make the government protect the patients' rights, eliminate discrimination and prejudice on the basis of a disease, and implement a policy to prevent recurrence of such violations is the patients themselves and the patients' movements. Patients are the subjects of human rights and not the objects. Having said so, however, we also see it showing that these patients and patients' movements cannot fight a battle without any support from the society. Hence, some crucial problems were left. The self-evaluation of the residents differs at this very point.

One of the biggest problems that were left is concerned with the question: "Why was it that the All-Japan National Leprosaria Patients' Association could not actively and subjectively fight again the Battle against the Prevention Law after 1975, when certain treatment was getting improved in sanatoria?" In order to fight, it was essential to defeat the argument that "compulsory segregation and treatment improvement are the two sides of the same coin" from the standpoint of the theories of constitution and human rights. This required support of legal experts. However, this responsibility was not fulfilled by legal experts. Some 25 years passed until some lawyers fulfilled this particular responsibility. It was way too late. In such circumstances, it was unrealistic for organizations like the All-Japan National Leprosaria Patients' Association to try to unite their opinions toward a second Battle against the Prevention Law.

Similar problems existed in residents returning to the society. In terms of the sanatorium self-governing associations helping them return to the society, many residents gave passive evaluation, such as the following: "There was no real effort to promote our return to the society, except they say they would." This, however, was because most of the reasons that the number of returnees to the society reached its peak around 1960 and went down subsequently were found on the society's side. Were there improvements made after the district court's decision? Did the society's attitude of responsibility-avoidance change? Aren't the residents still depending on their own effort mostly? Creating an environment for residents to return to the society and making preparations to receive them in the society are urgent tasks to be done. We would strongly urge quick, detailed citizen-participating actions based on the real conditions by local governments, etc. as well as financial backing of these efforts by the national government. Contribution based on self-criticism by experts related to social welfare, etc. is also indispensable.

Many problems also remain in battles against discrimination and prejudice. This society shows sympathy and understanding as long as recovered patients live quietly and passively as beings to be pitied. However, the same society does not show understanding if they try to stand up against the submission forced upon them. Instead, the society rejects such an action and sometimes even shows enmity. This "sympathy" theory, deeply planted in people's hearts through "Leprosy-Free Prefecture Campaigns," etc. is one side of the coin, the other side being "discrimination and prejudice without sense of discrimination." It is a job of a legal expert to defeat these notions in terms of the theory of human rights. However, this responsibility too remains unfulfilled, as evidenced by incidents like the I-Star Hotel Accommodation Denial case. The scholarly field of law remains almost silent, too.

The structure of "discrimination and prejudice without sense of discrimination" must be eliminated as soon as possible. It goes without saying that the primary responsibility belongs to the government, but the society also has an enormous responsibility. We wish to urge the bar associations, mass media, the religious community, etc. to take continual actions toward the extermination of discrimination and prejudice, to build a system to accomplish this goal, and to promote cooperation with other organizations and groups for this purpose.

Self criticism with respect to the method for movements of the All-Japan National Leprosaria Patients' Association also states that "appealing to the people and seeking its wide-spreading in the society had been neglected." This too is a challenge that the society on its side should be blamed for. Most of successive newspaper reporters lacked knowledge on the Hansen's disease problem, having never put their feet in a sanatorium for Hansen's disease. The system to allow coverage or interviews has also been weak. In the contemporary society, most of the problems that occur become known to the society when they are reported. The fact that reporters were not aware of the problems involving Hansen's disease is equivalent to annihilating the existence of the problem, socially speaking. What can we learn from this? This is a big challenge for the mass media.

In terms of cooperation with citizens' movement, we hope that those on the side of the citizens' movement will learn much from the movements of the All-Japan National Leprosaria Patients' Association and enlarge their network. We also wish to stress the need to cooperate with women's movements, but it is the responsibility of local governments, legal experts, the mass media, researchers, etc. to play the role of a coordinator for this end.

"The problem of Design for the Future" has been pointed out as today's largest challenge facing self-governing associations and the All-Japan National Hansen's Disease Sanatoria Residents' Association. The following points must be checked regarding this problem. "The government and the society must deeply acknowledge that they themselves are responsible for leading to the current state of affairs and take actions with sufficient understanding of the responsibility."

Certain needs of society support for the patients' movements are to be suggested such as the following: "a need for legal and civil support, as well as the significant roles that must be played by legal experts, the mass media, etc. for such support," "having multiple channels for respecting the opinions of a few, including judiciary," and "making preparations to receive those wishing to return to the society, such as society-returning support centers." These are not limited to the case with Hansen's disease. These are challenges shared by all patients' movements.

24. Response and Responsibilities of the Mass Media #14 (_2)

A. Characteristics of Each Period

The period between the end of the war and the end of 1953 saw very few news articles concerning Hansen's disease. One can easily see that news about Hansen's disease did not have a high priority unless accompanied by an element.of incident. In quantity, there were more articles pointing out the need to provide aids to patients of Hansen's disease, but they were all written from the perspective of compassion and charity, with tolerance to or acceptance of the compulsory segregation and confinement policy of all patients. In fact, there were some articles that seemed to encourage discrimination and prejudice against Hansen's disease. 1953 was the year when the revision proposal of the "Leprosy Prevention Law" reached the Diet, but the news only briefly reported that some patients of Hansen's disease made petitions and organized a sit-in to demonstrate. The articles said nothing about what was discussed about the revision of the Prevention Law, and papers did not function as an agenda setter as they should have.

The primary characteristic of the period between 1954 and 1960 is that the coverage increased. It was triggered by the report on the "Kurokami School Incident," mainly in the territory of (newspapers') western main offices, where the reports vividly described the conflict between the patients, opposing neighbors, and the government. Even more remarkable than the increase in quantity is the change in quality: reports were now from a "neutral position." Fujimoto's Case, which also occurred in Kumamoto but became news across the nation, was also reported from a "neutral position." Perhaps we could see that the conventional view on "leprosy" was shaking a bit. Although what makes us feel somewhat uneasy is that there was a little flavor of the traditional view of "rescuing leprosy patients," there was an increase in reports concerning external "leprosy rescue" activities. The number of articles supporting segregation (such as reports on patients going outside sanatoria as problematic) goes down during this period, but there were still a few remaining.

The period between 1961 and the end of 1975 can be divided into two sub-periods, separated by the November 4, 1964, article reporting the first "homecoming project" by Tottori Prefecture. In the first half of this period before that date, we could say the "shaking" seen earlier had further deepened. According to the decision by The Kumamoto District Court, the "(New) Leprosy Prevention Law" had already been unconstitutional by around 1960 at the latest, but there was absolutely no article questioning the relationship between compulsory segregation and the Constitution. There was no article found that dealt with a revision of the law or human rights violations.

This "shaking" of the old "leprosy" view underwent a significant change and "promoting understanding" became an underlying trend in newspapers during the second half of the period, after the above-mentioned report on the "homecoming project." Detailed reports were written about the project and its development from the standpoint of promotion of it. We could see this was a clear departure from the segregation-promoting view. Segregation-promoting articles disappeared completely. Articles seeking understanding of Hansen's disease and the patients of it followed, after the "homecoming project" report. These movements have a component "from above," directed by the Ministry of Health and Welfare, and a component "from below," symbolized by campaigns to host showings of the movie "Thick Wall." This latter component was picked up by the media, also. Perhaps these articles were not written from the standpoint of the theories of constitution or human rights, but the fact that they were written from a "neutral position" and the like was some degree of change in itself. It should also be pointed out that, starting May, 1965, the traditional terms "leprosy" and "leprosy patients (lepers)" were being replaced by expressions like "(Mr.) Hansen's disease" and "patients of (Mr.) Hansen's disease." Another characteristic is that, among reports on external "leprosy rescue" activities, a large proportion of them dealt with (South) Korea. The media was clearly conscious about the friendship between Japan and Korea. Reports on Okinawa were also numerous. However, in these external contexts, the traditional view of "rescuing leprosy patients" was still very strong.

Between 1973 and 1978, the coverage became extremely little. Perhaps there was a feeling that the problems involving Hansen's disease had already been resolved.

Articles between 1976 and the end of 1990 can also be divided into two sub-periods, separated by the December, 27, 1984, article concerning the decision to build the Nagashima Bridge. During the first half, between 1976 and the end of 1984, the emphasis was placed on "eliminating prejudice." The "understanding" of Hansen's disease and its patients was qualitatively shifting from the view of "rescuing leprosy patients" to "eliminating prejudice." *The All-Japan National Leprosaria Patients' Association News* on January 15, 1984, proposed a need to fight the Battle against the Prevention Law again. However, the media never picked this up as being significant. It is crucial to observe that this lack of coverage led to the All-Japan National Leprosaria Patients' Association and other groups to give up this second Battle against the Prevention Law and set a preliminary context to lead to giving them no option but to take only passive approaches in the revision and repeal of the Prevention Law subsequently. During the second half, beginning in 1985, the appearance of the term "human recovery" on the front page is a characteristic. This was triggered by the above-mentioned article on the Nagashima Bridge, which was reported very widely, led by attractive headlines such as "Bridge of Love."

Articles from 1991 to the end of 1996 could be characterized by "promotion of revision and repeal of the Prevention Law." They follow closely the movements of the All-Japan National Leprosaria Patients' Association and scholars in detail, and they began to emphatically support the repeal of the law, beginning around 1994. Regrets of the directors' council and of the Japan Leprosy Association were also reported considerably. Much paper space was also dedicated to the challenges remaining after the repeal of the Prevention Law. There were also articles for educating and informing the public through actual statements and remarks made by sanatorium residents. In addition to the previous term "human recovery," the term "human rights" have also become a key word.

B. Remarks

The media plays an enormous role in cleansing the society from discrimination and prejudice against Hansen's disease, in spreading correct understanding of it, to prevent secondary damage, to create "receiving plates" for necessary "human recovery" (including return to the society), and to build circles of support for these purposes. Looking at the media from these perspectives, since 1965, particularly since 1979, the media have been walking half a step ahead of the public opinion. This foresight could be commended.

However, the situation is quite different if one looks at the media from the perspective of what the sanatorium self-governing associations and the All-Japan National Leprosaria Patients' Association expected the media to report. The Battle against the Prevention Law, subsequent battles over improvement from the poor quality of medical care and welfare in sanatoria, starting with the battle to return work, a second battle against the Prevention Law, which was but a dream, etc.-sanatorium self-governing associations and the All-Japan National Leprosaria Patients' Association had hoped that the society support for all these things would be increased if and when the media decide to report on these issues widely. However, such a wish ended up like a "one-way crush." Even the so-called nationwide newspapers, media with relatively large printing areas, often pushed articles concerning Hansen's disease away to a "corner," according to the priorities based on editorial decisions that there was other news to be reported. This became one of the major factors for a second Battle against the Prevention Law not to be materialized but to end as an unfulfilled illusion. What the sanatorium self-governing associations and the All-Japan National Leprosaria Patients' Association had hoped for was reports prior to 1984; it is truly ironic that the "patients' movements," in which the media claimed to have taken the position of the patients, were the ones that had been dramatically affected by the government's view that "compulsory segregation and treatment improvement are two sides of a coin" while social support did not gain popularity. In other words, the "patients' movements" were the ones that had had no option but to change.

The real problem is why these "misses" took place. The media, which are strongly expected to function as an agenda-setter, are sought to maintain a higher level of interest in social challenges. The pain and suffering suffered by those who are oppressed in the society will eventually be spread to the entire society, bringing discomfort and a gloomy environment to more people. The feeling of discrimination and prejudice that progresses daily on a regular basis, as if it were the sense of touch, will lead to devastating damage in the future. However, many of the newspaper journalists in history and across the country did not learn enough knowledge concerning the problems involving Hansen's disease, nor did they ever step into a sanatorium for Hansen's disease. The system to allow interviews and coverage was also weak.

Many of the problems that occur in the contemporary society are made known to the society through a media report. And this has a big impact on the decision and opinion of policy-makers. For the press not to notice something is equivalent to the annihilation of the existence of the problem, socially speaking. When one is on the frontline of journalism, it is easy to see only the events that are odd or random. Journalists get busy with the daily task of editing the paper; it is said that the task of digging up a problem quietly hidden behind our daily life can tend to get postponed all the time.

Judgment of news value that media reporters have been required to make has had tendency to lean too much toward picking news and reporting those stories that the readers as a whole want to read about at the time. This extreme tendency is another challenge to be overcome. In the end, this tendency prevents reporters from paying attention to the voices of the few who need to be heard, who raise issues and problems with a high level of relevance. The result is that the starting point of news coverage-to see the existence of the frontline-could get overlooked for a lengthy period of time, as was the case from time to time. Furthermore, unconsciously or otherwise, the existence of discrimination and prejudice that settled in the hearts of reporters and editors was one of the major factors that led to their passive attitude toward reporting on the continuous and gross violations of the human rights of patients and former patients of Hansen's disease; this fact cannot be denied.

Most reporters gave up their opportunities to visit sanatoria and were powerless for the relief for the "hidden violations of human rights." The fact that reporters never put their feet in sanatoria was also evident in the coverage of Asia's rescue projects for leprosy patients, on which not only Project Departments but also some frontline reporters from Social News Desk worked together. The reporters in the Social News Desk should have been the ones most sensitive to the existence of the socially weak. Why then were they following stories of India and other Asian countries, without ever paying any attention to the sanatoria here in Japan?

The errors in handling the coverage of Hansen's disease were not just random events by any means. They were grounded in Japan's post-war media structure, which is a problem yet to be overcome.

C. Measures to Prevent Recurrence

A few things are to be suggested to individual reporters. They are "not just to follow and accept the *status quo* of the society's common sense and government policies blindly but rather to maintain an attitude of always questioning what's right and what's wrong with a critical eye." They are also to "pay attention to the voices of a few and stay diligent and creative to communicate their voices to the society."

There are also certain suggestions for newspaper companies. They are to "establish a system so that they can check for any crucial problem that needs to be exposed to the society that is hidden under the surface and should make an effort to dig up any omissions." They should further "have a 'public hearing' section where the readers can request coverage on some issues that the society holds within and/or where the readers can point out problems that beset the society; the paper should also disclose the contents of the section and resulting actions taken on a regular basis." Finally, they are to "take some measures to fill the wide gap between information communicated by the media and the information reported in scholarly journals."

25. Trend of International Meetings and Japan's Policy on Hansen's Disease #15 (_1)

A. Start of International Meetings

The first international meeting on Hansen's disease was held in London in 1862 (the end of Edo period) and was called the "Meeting to Find the Cause of Leprosy (Hansen's Disease)." The dominating opinion was that Hansen's disease is a hereditary ailment; only physicians from India believed that it was infectious. At this time, Japan had virtually no policy on Hansen's disease. Only some rescue work was being done by overseas missionaries and benefactors.

B. From 1900 to the 1920s

The First International Leprosy Conference was held in Berlin in 1897; the Second Conference was in Bergen in 1909; and the Third in Strasbourg in 1923. In these meetings, based on the theory that Hansen's disease is infectious, it was resolved that its prevention and medical treatment should be carried out within the framework of general law, and isolation should be limited to homeless patients. At the Third Conference, Kensuke Mitsuda stressed that isolation is the correct way to prevent a recurrence of the disease, but he got no support. Despite this, the "10,000 confinement plan," devised by Mitsuda, went on to be implemented, supported by nationalism (which considered Hansen's disease as a national embarrassment) and the theory of social defense (justifying isolation). After the World War I, Japan began stressing its independence of and superiority over European nations. Probably such political factors influenced the Japan's policy on Hansen's disease significantly

C. From 1930 to 1945

According to the reports from the Leprosy Committee of the League of Nations in 1930 (Bangkok) and from the International Leprosy Association meeting (Cairo), Hansen's disease should be handled as a part of public health problem, and isolation should be limited to exceptional cases. However, in Japan, the Ministry of the Interior publicly announced the "Extermination Policy on Leprosy," establishing the absolute segregation policy. In 1931, the (Former) Leprosy Prevention Law was enacted. Soon after that, in 1933, Japan withdrew from the League of Nations. Ignoring the international trend, Japan began implementing the segregation policy even in its East Asian colonies.

D. Post-War Trend: the Constitution of Japan and the Policy on Hansen's Disease

The Constitution of Japan was enacted in 1946, bringing in a new era that would guarantee human rights. In the same year, the World Health Organization (WHO) was founded. Japan began its participation in the WHO activities in 1955, the same year Japan joined the United Nations. Japan also sent participants to every International Leprosy Conference at the Sixth Conference and subsequent ones. After the war, Japan domestically succeeded in manufacturing Promin, a drug used to treat Hansen's disease, and medical treatment by this new medicine began.

Along with these events, Ryutaro Higashi, director of the Medical Bureau of the Ministry of Health and Welfare, gave an important speech in the Diet in 1948: he stressed the need to review and reconsider the absolute segregation policy due to the advancement of medicine such as the use of Promin. However, after this speech, there was no single word recorded concerning reviewing absolute segregation. It is thought that the opinions of those in Japan's medical field and of sanatorium directors like Mitsuda were reflected.

On August 6, 1953, the bill that contained the government policy to continue the absolute segregation policy was passed as originally stated, despite the desperate opposition against the revised Prevention Law by patients. No single person in the Japan Leprosy Association expressed the opinion that the "Leprosy Prevention Law should be repealed."

E. Post-War Trend: Continued Segregation Policy and Ignoring the International Trend

At the Fifth International Leprosy Conference (Havana) in 1948, the First Leprosy Specialty Committee of the WHO (Rio de Janeiro) in 1952, and the Rome Conference in 1956, discriminatory laws and systems against Hansen's disease and isolation facilities were rejected. Further, at the conference held in Japan – the Seventh International Leprosy Conference (Tokyo) in 1958, a resolution called for the government of each nation to abandon any type of isolation. Then, the importance of a policy for patients to return to the society was pointed out, based on that resolution. However, the Japanese government continued to refuse reviewing its absolute segregation policy.

Meanwhile, the Ministry of Health and Welfare was not completely ignorant of the international trend. It tried to take measures within the elastic operation frame of the (New) Leprosy Prevention Law without its revision, and was involved in the following: (1) return to the society (through welfare instruction projects, "Standards for Temporary Discharge of Leprosy Patients," and a system of stipends for employment assistance), and (2) outpatient treatment (through establishing a clinical facility in Nagoya in Aichi prefecture). However, what the international conferences and the WHO sought of the government of each country were review of discriminatory legislation and lifting of any mandatory isolation policy. The attitude of the Japanese government, which did not repeal the (New) Leprosy Prevention Law, was one of completely ignoring the international trend. The problem is deeply rooted in the sense that the government trivialized the statements of the WHO and other organizations.

There are several reasons why Japan ignored the international trend and did not repeal the (New) Leprosy Prevention Law. Here, the impact of the strict segregation policy from before the war is undeniable. First, the discrimination and prejudice of the people against Hansen's disease and the patients were deep, and the government was concerned about a big social hurdle if the law was to be revised. Second, not only the patients but also the medical science of Hansen's disease and the sanatoria for Hansen's disease themselves were all "isolated" from the society, and relevant information and reality were never communicated to the society. Third, sanatorium doctors and other medical professionals who could not attend international conferences after the war could not relate the international trend with the real problems of Japan.

F. Post-War Trend: Other Countries Abandoning Isolation and Japan Continuing It

At the Eighth International Leprosy Conference (Rio de Janeiro) in 1963 and the Third Leprosy Specialty Committee of the WHO (Geneva) in 1965, founded on the international trend through the 1950s, it was resolved that the government of each nation place a policy on Hansen's disease within general public health and repeal any laws that are discriminatory against Hansen's disease. Already, Asian countries except Japan had begun reviewing their isolation policies and shifting medical treatment to an outpatient basis. In the midst of these, a trend began in Japan, once again, to call for a revision of the (New) Leprosy Prevention Law, mainly through patients' movements. However, there was no sign that the Ministry of Health and Welfare would fundamentally review the segregation policy according to the international trend. They were just discussing improvement in living conditions in sanatoria, and they did not consider the problem serious. The Ministry of Health and Welfare did not get involved in revising the (New) Leprosy Prevention Law on the ground that the society in general feared Hansen's disease.

After 1970, the WHO shifted its activity emphasis to outpatient treatment as Asian nations except Japan had already been reviewing their isolation policies. Meanwhile, even though the repeal of the segregation policy was occasionally brought up in meetings of the Japan Leprosy Association, such an opinion never became mainstream. Consequently, the (New) Leprosy Prevention Law was not repealed until 1996.

G. Conclusion

We surveyed the relationship between the trends of International Leprosy Conferences, the WHO Leprosy Specialty Committee, etc. and the continuation of Japan's segregation policy. Japan began ignoring the international trend around 1923, when the Third International Leprosy Conference was held. The international political situation was very tense at the time, and Japan, choosing its own direction, opted for an segregation/confinement policy on Hansen's disease. In 1946, the Constitution of Japan brought in a new era, but the segregation/confinement policy from before the war was maintained both by the medical community and legislature. Japan joined the United Nations in 1955, but it refused to follow the directions of international conferences and the WHO concerning policies on Hansen's disease on the ground of domestic situation that the people's prejudice and discrimination on Hansen's disease were very deep. The government tried to handle it not by repealing the law but by elastic interpretation of the (New) Leprosy Prevention Law. Major reasons that the segregation/confinement policy was continued under the Constitution of Japan are considered to be the government's public security policy, etc., but another probable factor is the lack of interest on the part of the society because the long-term segregation policy, which existed from before the war, "isolated" not just the patients but also the medical field involved in Hansen's disease as well as the sanatoria for Hansen's disease themselves.

We would like to add one remark here, which has to do with the relationship between international conferences and the question of why Mitsuda so firmly stressed absolute segregation. At the Third International Leprosy Conference, Roja (who had been involved in medical treatment of Hansen's disease in India) reported that Japan has 100,000 patients of Hansen's disease. Mitsuda was indignant and lament over this report, saying, "Japan, a country proud of the purity of its own pedigree and blood, is now known as the world's leading leprosy nation, far worse than European and American nations." He was humiliated that "Japan, a country proud of the purity of its pedigree and blood," would be listed along with "barbarous, uncivilized, and primitive nations." This embarrassment led him to the forceful implementation of "absolute segregation just as with other infectious diseases." As implied by the sterilization of Hansen's disease patients which he began in 1915, he sought complete extermination of Hansen's disease from the perspective of eugenics, too. Absolute segregation was not just because of national shame; it was also a part of his eugenic policy. Japan's policy on Hansen's disease had already been given such a direction, and even the trend of international conferences could not be tolerated.

26. Transition in the U.S. Policy on Hansen's Disease #15 (_2)

A. Purpose of the Discussion

To study Japan's absolute segregation policy, here we look at the United States' policy on Hansen's disease, from the viewpoint of international comparison. Violation of human rights of patients of Hansen's disease was also quite significant in the United States. Discrimination against patients of Hansen's disease was also linked to racial discrimination against African Americans and Hispanic immigrants as well.

However, we must not naively conclude from this that human-rights violation against patients of Hansen's disease was universal, common around the globe. This is because the proponents of Japan's absolute segregation policy criticized even the isolation policy of the United States. A comprehensive policy that functioned to bring about compulsory segregation, mandatory sterilization, mandatory abortions, mandatory labor, and imprisonment until death-such consistent and thorough violation of human rights did not occur anywhere except in Japan and its colonies.

B. Extent of the Discussion

In the United States, legislature, administration, and government policies exist at two levels: the level of the federal government and the level of the state government. Sometimes they are independent, and sometimes they supplement each other. Since the judicial and executive systems differ between Japan and the United States, there are limitations in comparing, side by side, the changes in laws of the two countries in a simple way. However, it is worthwhile to study, comparatively, the factors that prevented the cooperation between medical and scientific advancement and the medical and public-health policies in the two countries. This is in fact one of the crucial tasks in identifying the characteristics of Japan's policy on Hansen's disease from an international viewpoint, taking into account the universality of the society and government policy and administration. This, however, requires an enormous amount of labor because there is no literature of general history concerning policies on Hansen's disease even in the United States. Hence, for this report, we had to settle with simply listing and introducing major public documents regarding the United States' policy on Hansen's disease and describing the transition of the policy on Hansen's disease posed by the federal government.

C. Transition of the Policy (Isolation Policy) on Hansen's Disease by the United States' Federal Government

The federal government of the United States established a facility in Hawaii in 1905, authorizing the Surgeon General to place patients of Hansen's disease there for the purpose of research and medical treatment. In 1917, legislation was passed to open a national sanatorium for leprosy, to give the Surgeon General authority to carry out mandatory admission, and to pay "danger stipends" to those who work at the sanatorium. In 1922, a sanatorium began its operation in Carville, Louisiana. A sanatorium medical officer in the 1920s stressed repeatedly that, while it is not a crime to be inflicted with Hansen's disease, if a leprosy patient is detained, it is a crime against the society for the patient to run away from the detention and expose others to the danger of this incurable disease and that prevention of the disease requires the isolation of all patients. Meanwhile, the medical officer of the Public Health Bureau of Hawaii said that it is difficult to imagine that isolation had contributed significantly to the decrease in the incidence of Hansen's disease in the state, that the incidence and the propagating mechanism of the disease are yet unknown, and that isolation should be continued on economic and humanitarian ground. Note that both of these officers supported the isolation policy. Whether or not these mandatory means by police force are realistic was thought to depend on factors like the incidence ratio of the disease, the policy and economic power of the designated department of the government, information communication and transportation methods within the region, and whether or not confinement (living) can be accepted as a substitute for individual freedom. Only about 15% of the patients admitted there between 1930 and 1945 were said to have been voluntarily admitted. Those who escaped from the sanatorium were placed in the prison inside the sanatorium without an official trial.

Application of Promin to patients of Hansen's disease began in 1941 at the sanatorium, and its effect was gradually reported. The use of chaulmoogra oil at the sanatorium was stopped in the fall of 1947, and sulfone became the first-choice drug. With the introduction of these effective medicines, the number of patients discharged as "non-active (arrested)" increased. Experts in those days maintained the need of isolation in infectious and open cases but opposed total isolation without considering the medical conditions. For example, Faget, director of the sanatorium, stated as follows: "The only sure method to exterminate Hansen's disease is patient isolation. This is because, when there is no specific medical treatment and the exact infection route is uncertain, the only method for controlling the disease is the isolation of cases inflicted with the infectious disease. However, mandatory isolation fails since it is an infringement of individual freedom, so voluntary isolation should be promoted." "With more than 4 years of use, the validity and effect of sulfone have been well established as a chemotherapeutic treatment, and it is becoming the number-one treatment method." Because of this fact, he said, "it is more critical than before to educate the infected patients and their families so that more patients would go to the sanatorium voluntarily in an early stage of their infection." Meanwhile, McCoy, who had retired from the Public Health Service, wrote the following in the same journal in 1948: "We need to be constantly careful with the possibility of recurrence in non-active (arrested) cases, but the level of danger of infection varies considerably depending on the clinical type. A policy that attempts to put every patient in isolated confinement does not consider the possibility that some patients do not pose any threat to the society; therefore, such a policy should be abandoned." Additionally, he stated that if there is any doubt concerning the possibility of infection, the benefit of the doubt should be given to the patient's freedom and stressed that only those patients considered contagious should be isolated, as already done by the Norway's Health authorities.

However, the Public Health Law, enacted around the same time, in 1944, included the authority to execute compulsory confinement, basically succeeding the old legislation. In other words, it stipulated that patients of Hansen's disease who voluntarily came forward for care, confinement, and/or medical treatment, patients that the director of the Public Health Service considered necessary to be isolated, and patients that the public health authorities of a state considered necessary to be treated by the federal Public Health Service were to be admitted to the hospital of the Public Health Service, and mandatory enforcement could be invoked when it was necessary for confinement and medical treatment. On the other hand, the standard for discharge due to improvement was also revised. Even a patient in contagious stage can be medically discharged by the director if the patient satisfied certain criteria (the patient's family is financially able to support treatment; the primary physician is to continue care and to report every month to Carville; the state's public health department of the patient's domicile agrees; the family to which the patient is returning has no children and has only a few adults, etc.) As a result, in July, 1948, a first patient was discharged, followed by another a few months later. Laws and regulations regarding the treatment of the residents were also revised from time to time. In 1946, residents were given the right to vote; in 1948 the barbed wire fence surrounding the sanatorium's outside wall was removed, and a post office was opened on the premises of the sanatorium. Laws were established to provide public funding for patients returning to the society (a challenge that arose with an increase of discharged patients) so that the recovered patients were reimbursed for moving and transportation fees and living expenses while moving. Further, in 1949, a school was built inside the sanatorium, and in 1952 marriages were allowed as well as the use of the telephone. However, even though a campaign to revise the law in order to eliminate mandatory confinement was continued to the early 1950s, the revision did not materialize, mainly due to opposition of the Public Health Service.

In the 1950s, a policy was proposed to discharge patients in general so that they could return to the society, but sufficient effects were not gained due to opposition by patients' groups, etc. Edgar B. Johnwick, who became a new director in 1956, addressed the residents on the third day of his job and declared the following statement: "No one shall leave this sanatorium against his will. No one shall stay in the sanatorium against his will." Two years later, in 1958, the disinfecting procedure on the mail was stopped.

In 1960, on the location of a patient-owned building that had been demolished by the previous director, new residential buildings were constructed for married couples. Thus, the sanatorium was renovated gradually according to requests by patients (or the Patient's Federation). The last mandatory admission to this national sanatorium took place in this year, 1960. In the middle of the 1960s, there were about 300 residents in the sanatorium. Prior to the discovery of sulfone, Hansen's disease used to require a stay for a very long period of time, sometimes the entire life, at the sanatorium; however, by the mid-60s, newly diagnosed patients would stay for an average of less than 5 years in the sanatorium. This depended on reaction to medical treatment, but some of them were reported to be discharged within a year.

In the 1980s, from the perspective of a national financial reform, public services were restructured and reduced. Bills to rename the sanatorium National Center for Hansen's Disease and to revise the United States' policy on Hansen's disease were submitted to Congress several times. At the 99th Congress in 1980, "Hansen's Disease Program (PL 99-117)" was adopted, and significant revision of the law was made concerning Hansen's disease. The new legislation stipulated the following: (a) the Secretary of the Federal Health and Human Services shall provide free treatment and care (including outpatient treatment) at the Hansen's Disease Center in Carville to any patient of Hansen's disease who needs and requests for treatment and care; (b) the Secretary shall appropriate an equivalent budget to the Board of Health of the state of Hawaii as to the Center of Hansen's Disease on the mainland; and (c) the Public Health Service Facility in Carville (sanatorium for Hansen's disease) shall be renamed "Hansen's Disease Center." A 1984 law and a 1985 federal regulation banned new payment of any special stipends given to medical staff members involved in treating Hansen's disease, but payment of such stipends was continued to those who had been employed on a full-time basis for at least 30 days as of 1986. However, additional pay was cut from ½ to ¼. With this law, mandatory admission was deleted from legislation

Based on this law, the Public Health Service prepared the document "Strategic Plans for the National Project on Hansen's Disease" in 1988. This project consists of the Hansen's Disease Center (the sanatorium) in Carville and eleven local centers. These plans discuss how projects should be carried out and state some conclusions suggesting certain changes such as the following: the Center (sanatorium) should extend its services to include diabetes and other diseases causing nerve failures; care-taking of long-term patients should be outsourced; the research facility should be moved to Baton Rouge; while the Center (sanatorium) must continue to provide lifetime care to those current resident patients in accordance with the government's commitment, the Center (sanatorium) should not admit any new patients for lifelong care; and the number of residents should be decreased until the closure of the Center (sanatorium) in the future.

After this, the medical treatment of acute cases and research and education facilities of the sanatorium were moved to the state capital Baton Rouge, and the admission of new resident patients was essentially terminated in 1988. In 1997, the admission of long-term resident patients to the sanatorium was officially banned by law.

27. Hansen's Disease Policy in Okinawa and Amami Regions #16

A. Meaning of the Discussion

In the decision of the Kumamoto District Court, the segregation policy on Hansen's disease in the Okinawa and Amami regions after the war prior to their reversion to Japan was not sufficiently discussed. However, in fact-finding on problems with Hansen's disease in Japan, research on the segregation policy on Hansen's disease in the Okinawa and Amami regions after the war and before their reversion to Japan turns out to be indispensable.

In particular, the verification study of the history of the segregation policy in the Okinawa region is significant in light of the severe damage due to the battle of Okinawa (cf. Miyako Anna's Society, ed. *Beyond the War: Testimonies from Miyako Nansei En*, 2000, etc.). The study is also significant because it is often believed that the policy changed to open policy after the war.

B. Period Division

The history of the segregation policy on Hansen's disease in Okinawa can be divided into five periods. The first begins in 1910, when the prefecture of Okinawa stipulated the details of the implementation of the Matter concerning the Prevention of Leprosy. The second period begins in 1927, when Okinawa separated from the jurisdiction of the Kyushu Sanatorium; during this period, sanatoria were built and the absolute segregation policy in a unique sense began in Okinawa. The third period begins in 1944, when large-scale compulsory confinement was carried out by the imperial military of Japan. The fourth period begins in 1945, when the segregation policy was undertaken by the United States government. The decision of the Kumamoto District Court stated that the damage conditions due to the segregation policy were unproved during this fourth period. This period can be subdivided into three sub-periods, separated by the 1952 establishment of the Ryukyu government and the 1961 enactment of the Law for the Prevention of Hansen's Disease. The fifth period begins in 1972, when the (New) Leprosy Prevention Law began to be applied.

C. Overview

During the pre-war era, i.e., the first and second periods, Japan's segregation policy, which gained momentum in the 1930s, was powerfully implemented in Amami and Okinawa, where patients of Hansen's disease were many. For instance, while the population of Okinawa is about 1% of the total population of Japan, 1 out of every 10 residents of sanatoria was in Okinawa, meaning that the force of the segregation policy was 10 times as much. We have discovered from journal entries of the Japanese imperial military, etc., that during the third period (during the war), compulsory confinement was carried out by the 9th division and the 24th division in 1944. Further, from journals of the then Airaku En self-governing association, etc., we have found out and confirmed that as the number of the residents was twice as many as its capacity due to this large-scale confinement by the Japanese military, they lived extremely severe wartime living conditions in the sanatoria.

Further, after the war, during the fourth period (prior to the reversion to Japan), there was first a harsh compulsory confinement policy carried out in Amami by the United States military. After the islands was returned to Japan in December, 1953, the segregation policy was implemented again, this time under the (New) Leprosy Prevention Law, which was enacted in the same year. We surveyed the situation in Okinawa during this period by subdividing the period into three sub-periods after the war. The results of our research verified that the reality of damage in this region by the segregation policy, which the decision of the Kumamoto District Court found it unproved, was no different from the reality of that in the mainland.

D. From the Conditions after the War

Finally, we study the fifth period (after 1972) through the development of the sanatorium self-governing association movements at Airaku En and Nansei En as Okinawa was returned to Japan in that year.

The All-Japan National Leprosaria Patients' Association held its 19th meeting of branch presidents at Kuryu Rakusen En on May 15, 1972, the very day when Okinawa was returned to Japan. There, the representatives of Airaku En and Miyako Nansei En were welcomed by a resounding applause, officially joining the All-Japan National Leprosaria Patients' Association. At that time, Airaku En requested that the All-Japan National Leprosaria Patients' Association give instruction to them concerning self-governing association movements. Next month, three officers of the self-governing association of Hoshizuka Keiai En of Kagoshima visited the two sanatoria in Okinawa for the purpose of "clerical instruction related to the budget." This visit is a well-known and well-discussed topic even today at Keiai En. The story is that, as soon as the three took their first step into Airaku En, they were appalled, thinking, "This is horrible. This is like Keiai An in the mid-40s." Housing and food were awful, doctors and nurses were few, and it was not at all like a medical treatment facility. It appeared that activities in self-governing association movements was also behind the times, and they seemed to have no knowledge in negotiating with the sanatorium or how to request a budget. When stipend for labor was discussed, the sanatorium people asked, "What are you talking about? What is it?" This is a question that shocked the three visitors. They also had to coach the residents about organized movements by the self-governing association from the very basic things. Things have changed, and now it is said that sanatorium self-governing associations of the mainland are saying things like "Let's catch up with Okinawa," but back then, the cry of "at least like the mainland" was the desperate hope of Okinawa in every single aspect. The three representatives then went to Miyako Nansei En. There, they found that instruction from the All-Japan National Leprosaria Patients' Association was almost unnecessary. In fact, their facility, medical treatment, food, and other things were far more advanced than those of Airaku En, pretty much at par with the mainland. Organization of the self-governing association was also not much different as young leaders were communicating with the Association and self-governing associations at mainland sanatoria to collect information and study.

There was one thing with which Okinawa's sanatoria were more blessed than those of the mainland: their return to the society on the ground of discharge due to improvement. Actually, this too has a story behind the scene. It has been said that the Ryukyu government did not have sufficient funding for the sanatoria, so they encouraged discharge in order to cut their operating cost. However, there is no question that the outpatient treatment system that was unique to Okinawa contributed to this also. One thing to note is that the U.S. military occupation actively accepted these returnees. The American military quickly changed their attitude when they discovered that Hansen's disease is curable. They hired many former patients as long as they had a proof that they were discharged due to improved symptoms, even if some had no resume and some were disabled, fully knowing that they had been in sanatoria before. About 9 out of 10 former patients who returned to the society went to work on U.S. military bases, doing things like managing warehouses and unloading cargos. Just as the reality that Okinawa has to depend on the military-based economy, the returnees too lived an irony that they were making their livings by the United States military, who had caused them much pain.

At Airaku En, there is a general rule that everyone does everything together. This includes not only events but also gatherings of the self-governing association, where traditionally everyone that is healthy enough attends them. With respect to the Government Liability Lawsuit, initially there was a lot of hesitation; however, in the end, over 90% of the residents became plaintiffs, again showing the strength of their sense of unity. Today, discrimination and prejudice against Hansen's disease are still said to be deep in Okinawa, but at least the environment surrounding their sanatoria is clearly changing for the better.

Prior to June 30, 1961, when the "Law for the Prevention of Hansen's Disease of the Ryukyu Government" was enacted, the patients' self-governing association at Nansei En joined hands with Okinawa Airaku En, demanding changes in a bill prepared by the Ryukyu government, and even preparing a counter proposal for the bill to correct it. Some say that these negotiations resulted in the fact that this law contained the stay-at-home treatment option, which was not in the (New) Leprosy Prevention Law for the mainland. In April 1962, the self-governing association was involved in a large-scale, two-week-long battle over improvement of medical care and living conditions. They kept officers of the Welfare Bureau of the Ryukyu government in a public hall inside the sanatorium and held them there for negotiation; they successfully obtained 6 new nurses. However, for fundamental improvement in the treatment of the residents, they had to wait until 1972, when the islands were returned to Japan. The patients' self-governing association joined the All-Japan National Leprosaria Patients' Association when the islands were returned, and they are members to this day. We must also mention discrimination and prejudice. The United States military initially carried out thorough isolation over the sanatorium residents. However, they were quick to change once they discovered that Hansen's disease is curable. American soldiers often paid goodwill visits to Nansei En on Saturdays. Using baseball equipment, which had survived air raids and bombings because it was hidden in an air-raid shelter, they played friendly baseball games with the sanatorium residents. At each game, they shook the residents' hands and touched them quite naturally with no concerns whatever. Mr. Jiro Yonaha, who once was the president of the residents' self-governing association, made the following comment: "People on the island heard that American soldiers had no problem coming in physical contact with the sanatorium residents and picking up children to hold them. I feel that these things helped eliminate some of the discrimination and prejudice in the island."

However, Miyako Island is a place where traditionally discrimination and prejudice are deeply rooted. When the self-governing association tackled with the application for membership in the federation of senior clubs at the city of Taira, the problem was not resolved without great difficulty. Petitions were made to the mayor, and many request documents were submitted repeatedly, only to be rejected. However, once it was decided that the (New) Leprosy Prevention Law would be repealed, the federation completely turned around, and the membership was accepted on the very day when the Law was repealed. Residents point out that it is undeniable that the Law provided a ground for discrimination and prejudice.

28. Hansen's Disease Policy in Former Colonies and Regions Occupied by Japan #17

A. Treatment and Policy on Patients of Hansen's Disease in Former Colonies

1. (South) Korea

1) Sorokuto Jikei Hospital

Japan invaded the Empire of Korea and colonized it by establishing the Korean Governor General's Headquarters in 1910. The Headquarters accepted the opinion of Masaji Yamane, the Public Health Advisor, founded Sorokuto Jikei Hospital under the control of Jeollanam-do, and started to segregate patients of Hansen's disease.

There is not much documentation left from those days to reflect the conditions of this sanatorium in its early days. One patient who (at that time) entered Sorokuto recollects after the war: Akira Arikawa, the hospital director, "forced the Japanese way of living on resident patients" (*Oh, 70 Years, Shining, Sad Sorokuto*, Tosho Shuppan Toho, 1993). The patient also said, "Patients were under strict control in daily living. Communication with and visitation by family were limited, and temporary return home was almost impossible. Staff whipped patients who did not obey the rules as punishment" (ibid.).

2) Establishment of the Korean Leprosy Prevention Association

In the 1930s, Japan's strategy for Hansen's disease was the development of its absolute segregation policy, and this extended to Korea also.

The Korean Governor General's Headquarters determined that it was necessary to build one large sanatorium and put homeless patients of Hansen's disease into it. They sought private donations to cover most of the funds required to build the sanatorium, so in 1932 they established the Korean Leprosy Prevention Association.

3) Opening of Sorokuto Kosei En

On September 14, 1934, by promulgation of the Korean Governor General's Headquarters Regulation on Leprosy Sanatorium (Imperial Decree No. 260), the already existing Sorokuto Jiei Hospital in Jeollanam-do was expanded and became the Korean Governor General's Headquarters Leprosarium. By the Headquarters Order (No. 98), dated September 29, 1934, it was renamed Sorokuto Kosei En, and Suoh became its first director.

On April 20, 1935, the Governor General's Headquarters, following the "(Former) Leprosy Prevention Law," established and issued the "Korean Leprosy Prevention Order (Regulatory Order No. 4), which was a legal measure to manage patients of Hansen's disease. Under this regulation, the segregation policy was enhanced.

4) Life at Kosei En

The first problem is sterilization. By 1941, "sterilization" procedure was performed on some 840 married couples, but it was sometimes done as punishment. Testimonies say that sometimes sterilization was performed because the person cut a tree, escaped, or was simply rebellious, or anti-Japanese (December 22, 1997, TBS-affiliated *News 23 Special*: "Another Form of Forced Birth Control: Mandatory Sterilization in the Korean Colony").

Ryo Miyagawa was the clerical officer of Aisei En who accompanied Kensuke Mitsuda, director of Nagashima Aisei En on his trip to Kosei En in July, 1936. His memorandum on this trip "Leprosy in Korea" describes patient abuse by a staff member.

5) Kosei En under the Wartime Structure

After 1936, Kosei En underwent its second and third expansion construction projects, and the capacity ended up being about 6000 patients. In July 1937, the China-Japan War of full scale began, and Japan went into a wartime structure. With the war, Japan's economy worsened, and colony control became even more severe. Sorokuto Kosei En entered the harshest stage since its opening.

During the war, in order to ensure that patient laborers actually work under this severe condition, chief nurses, most of whom were former police officers or military police officers, monitored their labor very strictly.

The resident patients were forced to worship at a shrine on the first and fifteenth days of every month and to bow down to a bronze statue of Suoh, the sanatorium director, on the twentieth day of every month. They were also required to participate in patriotic group meetings every Monday and Wednesday and current events lecture series occasionally held. The way Suoh ran Sorokuto Kosei En was influenced by the social situation of the day, where Japan considered Korea as a military logistic base.

6) Interviews with Residents

The Verification Committee members paid a survey visit to Korea's Sorokuto Hospital from January 7 to 9, 2005. We were able to hear from two residents. A male born in 1921 testified that he was sterilized because he refused to worship at a shrine.

As seen above, the policy on Hansen's disease in the Korean colony, represented by Sorokuto Jikei Hospital and Sorokuto Kosei En, was a part of the absolute segregation policy for Japan, and Korean patients of Hansen's disease suffered at least the same level of violations of human rights as Japanese patients. However, the level of damage put upon them far exceeded the level suffered by patients in Japan due to the ethnic discrimination sentiment against a people in the colonized land added to the violations of human rights. This is typified by sterilization as punishment or beating of residents using a whip. It is an undeniable fact that Korean patients of Hansen's disease suffered a two-level human-rights violation caused by discrimination against patients of Hansen's disease and discrimination against a colonized people.

2. Taiwan

1) Opening of Rakusei In

On April 17, 1895, a peace treaty was signed to end the Sino-Japan War, and Qing ceded Taiwan to Japan, who established the Taiwanese Governor-General's Headquarters there, beginning its occupation of the colony Taiwan.

In the mid-1920s, Kensuke Mitsuda, director of Zensei Hospital, submitted "Comments Concerning the Enactment of the Taiwanese Leprosy Prevention Law" to Takio Izawa, the governor-general of Taiwan. There he stated that while only 200 patients were in Jikei Hospital, which was established by the governor-general in Korea, a sanatorium, which the American MTL established on the Christian doctrine, had 1200 patients. He pointed out that here it would cause some "Great-ism by the Koreans," warning that colonial rule itself would be threatened if the policy on Hansen's disease at a colony is entrusted to Europeans and Americans.

Accepting this document from Mitsuda was the new governor-general of Taiwan, Mitsunoshin Ueyama, who assumed the position in 1926. He started to appropriate budget for a 3-year plan to build a sanatorium, beginning in 1927. In December, 1930, he opened Rakusei In with a capacity of 100; Yutaka Kamikawa became the first director of the sanatorium (Rakusei In of the Taiwanese Governor-General's Headquarters, *Annual Statistics of 1930 and 1931*).

On June 15, 1934, the imperial order "Leprosy Prevention Law" was issued in Taiwan. On September 22, the Governor-General's Headquarters Order "Details for the Implementation of the Leprosy Prevention Law" was issued; both went into effect on October 1. The "Leprosy Prevention Law" of Taiwan was almost identical to the "(Former) Leprosy Prevention Law" of Japan. Kuraharu Ishigaki, director of the Police Bureau of the Headquarters, expressed his expectation for this law as follows: "Finally, the leprosy prevention task of Taiwan has gone beyond the traditional and halfway leprosy rescue projects and is about to shift to the extermination project by the segregation law" (Kuraharu Ishigaki, "Taiwan's Leprosy Problem," *Shakai Jigyo no Tomo (Friends of Social Work),* No. 67, June, 1934).

2) Life at Rakusei In

The capacity at Rakusei In, originally 100, gradually increased. It was 427 in 1937, grew to 587 in 1938, and reached 700 in 1939. This turned out to be the maximum capacity.

In June, 1934, Kensuke Mitsuda, director of Nagashima Aisei En, visited Rakusei In. On this visit, Mitsuda proposed that Taiwan also start a campaign for "33-square-meter residences." Immediately Eiki Yamamoto, a resident of Taipei, donated supplies and materials for one building to Rakusei In; in August 1935, the first "33-square-meter residence" was completed. Donations continued, and by June 1937, five more "33-square-meter residences" were completed (Kenzo Sakurai, "33-Square-Meter Residence Campaign for Leprosy," *Shakai Jigyo no Tomo (Friends of Social Work)*, No. 103, June, 1937). Segregation was thus extended. Following Japan's "Leprosy-Free Prefecture Campaign," a "Leprosy-Free State Campaign" was proposed. For this purpose, further donations for "33-square-meter residences" were sought (Nanzan Sakuma, "Wish of the Leprosy-Free State Campaign," *Manjuka*, Vol. 4, No. 2, June, 1937).

Kamikawa strongly demanded self-awareness as "the emperor's people" to all residents of Rakusei In. The year 1940 was the "imperial year 2600," and Kamikawa used Empress Komyo and Empress Teimei to speak of the "compassion" of the imperial family toward patients of Hansen's disease (Yutaka Kamikawa, "An Appeal to the Taiwanese People on the Leprosy Prevention Day on the Ten-Year Anniversary of Taiwanese Leprosy Rescue Project," *Manjuka*, Vol. 7, No. 3, August, 1940).

3) Interviews with Residents

The Verification Committee members paid a survey visit to Taiwan Rakusei Sanatorium from January 23 to 24, 2005. We were able to hear from five residents. It became quite evident that mandatory sterilization and mandatory abortions were performed during Japanese occupation and that these things continued even after the war in the 1940s.

The policy on Hansen's disease carried out by Japan in its colony Taiwan was a part of the colonial rule and was almost identical to the segregation policy within Japan. Patients of Hansen's disease in Taiwan went through and suffered the segregation policy just as patients of Hansen's disease in Japan did; however, in addition, they also suffered persecution due to colonial rule, i.e., persecution of segregation in order to protect the Japanese living in Taiwan. This is a crucial point to consider when studying the damage suffered by patients in Taiwan.

3. "Kanto Shu", "Manchuria"

1) "Kanto Shu," "Manchuria"

By the Russo-Japanese Peace Treaty singed on September 5, 1905, Japan got the right to lease Lushun and Dalian of the Liaodong Peninsula of China from Russia. Japan was also given the right to manage the Southern Manchurian Branch of the Toshi (East China) Railroad. The leased land of the Liaodong Peninsula was renamed "Kanto shu" by Japan, who established the Kanto Governor-General's Headquarters there to begin virtual colonial rule. As for the railroad, Japan founded the Southern Manchurian Railroad Company ("Mantetsu") in 1906, beginning the management of the railroad and mines, etc. along it. Triggered by the Ryujoko incident on September 18, 1931, Japan brought about the Manchurian Incident; the Kanto military occupied the northeastern region of China, known as "Manchuria." On March 1, 1932, the country "Manchuria" was established, which was essentially ruled by Japan until 1945. Japan advertised that it would build a "royal paradise" in the country of Manchuria, but it was in reality a puppet country controlled by Japan. "Kanto shu" and the country "Manchuria" were essentially two more colonies of Japan. Here we survey the policy on Hansen's disease in these two territories.

2) Juzo Iino's Involvement

When studying Japan's policy on Hansen's disease in "Manchuria," the name "Juzo Iino," a pastor, cannot be forgotten. Iino got interested in the problems involving Hansen's disease in "Manchuria" on his two trips, in 1921 and 1929, respectively, for missions in "Manchuria" and Korea. In 1933, Iino went on his third trip to "Manchuria" and Korea, establishing the Manchuria Leprosy Association in "Kanto shu." The reason he took this action is to spread the "imperial compassion" of Empress Teimei in "Manchuria" to strengthen the rule of Japan.

3) Opening of Doko In

In November, 1939, north of Mukden, about two hours from Tieling, in a place called Songshangbei, Doko In was opened; it was the national sanatorium for Hansen's disease in the country "Manchuria." Songshangbei has no residential homes. It was literally a place of segregation for patients of Hansen's disease.

The first director of the sanatorium was Rokuma Kawakami, head of the Quarantine Section of the Health Bureau under the Civil Division of the country "Manchuria." In January, 1940, the second director assumed the position: Masashi Nanba, who was the medical officer at Nagashima Aisei En. Doko In published a booklet called "Jiko (Compassion Light)" in May of that year. Currently, the only document remaining about Doko In is this booklet "Jiko."

Below, we describe the situations of Doko In, based on this booklet "Jiko."

First, in the "Introduction to Doko In," it is estimated that "the number of leprosy patients in Manchuria is currently about 300." The capacity of Doko In was 60, but the booklet optimistically states that the expansion of the sanatorium every year would "result in a Manchuria without a single patient." It goes on to describe that Doko In was opened as a preventive measure since it is expected that mainland China has about 1 million patients of Hansen's disease while "the number of leprosy patients in our country (Japan) is relatively small."

As of April 1940, the sanatorium had 1 Japanese, 10 "Manchurians," and 20 Koreans, a total of 31 patients. For them, there was one medical officer and three nurses. By the way, at Doko In, Japanese and Korean patients were supposed to be confined to the "Japanese building," white Russians to the "Russian building," and Manchurians and Mongolians to the "Manchurian building." The accommodation was ethnically segregated. Doko In was self-praised as a symbol of a "royal paradise." It was Kensuke Mitsuda, director of Nagashima Aisei En, who sent Madashi Nanba as the sanatorium's second director. Mitsuda was hoping that Nanba would "clean up the continent"; this was an idea found in his writing "Cheers for the Holy Task: a Message with Which to Send off Director Nanba of Doko In."

4) Later

There is no document from which we can find any details of Doko In after this. One can only speculate the destiny of Doko In, considering that the Japan's loss in the war caused the destruction of the country "Manchuria" on August 15, 1945, as the concept of "royal paradise" of the country "Manchuria" never materialized.

B. Treatment and Policy on Patients of Hansen's Disease in Japan-Occupied Territories

1. Occupied Regions in China

The Marco Polo Bridge Incident of July 7, 1937, put Japan in the state of comprehensive war with China. Until Japan's loss on August 15, 1945, Japan occupied and ruled a large territory including not only the northern and middle portions of the country but also the southern parts of the country including Hong Kong, Guangzhou, and Hainan Island.

The conditions of patients of Hansen's disease in China under Japanese occupation are written in detail in "Leprosy Problem in Southern China and the South Seas" (*Southern Medical Journal,* July, 1942) by Yutaka Kamikawa, director of Rakusei In, the sanatirum for Hansen's disease built by the Taiwanese governor-general's headquarters.

Kamikawa introduced an estimate of 1 million patient of Hansen's disease in all of China, adding that, "There is no question that China is one of the major leprosy-inflicted countries in the world today and that most of these leprosy patients are in the middle and southern regions of China." He then introduces the survey result of the city of Guangzhou, published in Vol. 40, No. 6 of *Taiwan Medical Society Journal,* written by Shuto Hirose, chief physician of Rakusei In. According to it, 84 patients of Hansen's disease were found out of 52,442 who were medically checked there. 16 patients out of 10,000 in the population is a high percentage.

What type of treatment did Chinese patients of Hansen's disease receive under Japanese occupation? Our findings are based on "Report on the Basic Survey concerning Disease Prevention," edited by the Mid-China Department of Communications of Koa In (Asia Promotion Institution), May, 1942. This document is a report of the survey that this department carried out by commissioning it to the Mid-China Central Quarantine Section of Dojin Kai in June, 1941, including a "Survey Report concerning Leprosy" by Itaru Takada, director of the Jiujiang Diagnosis and Quarantine Team of Dojin Kai. Jiujiang is a city along the Chang Jiang, between Nanjing and Wuhan. In it, there is a description concerning Wuyangzhen near Jiujiang: "When our military entered the castle, there were 40 or 50 leprosy patients, but the military, after entering the castle, made an effort to send these patients back to their registered home. As a result, at the time I made this survey, there was only one patient found." In other words, almost all of the 40 to 50 patients of Hansen's disease that existed when the Japanese military took over Wuyangzhen were almost entirely swept away. In Nanchang, on September 11, 1940, a Japanese military police unit wrote the following about Nanchang Mafu Hospital, a hospital exclusively for Hansen's disease managed by an American: "there would be a risk that it would be used for the enemy's strategy." Then it reports that, "the military is considering various plans for the Nanchang Subgroup of the Jiujiang Diagnosis and Quarantine Team of Dojin Kai to manage the hospital."

2. Southeast Asia

Japan, starting with the occupation of northern French Indochina in 1940, took over southern French Indochina in 1941, and Malay, Singapore, Dutch East Indies, and the Philippines in 1942, in its conquest of southeast Asia. There is only fragmented information on the treatment of patients of Hansen's disease in these territories under Japanese occupation.

In French Indochina, under the control of France, "the absolute segregation policy was not adopted; rather, many leprosy villages were made in appropriate regions" (Yutaka Kamikawa, "Leprosy in Southern China and the South Seas, and Taiwan," *Shakai Jigyo no Tomo (Friends of Social Work)*, No. 152, July, 1941) but Kamikawa criticized this strategy as a "random, no policy" after the occupation of Japan, demanding that "a well-equipped leprosy sanatorium be built in each of the major cities" (ibid.).

In the Philippines, when Japan and America began to fight, the United States were using open treatment; they had opened five sanatoria across the Philippines, putting only severe patients in confinement at the sanatorium on Culion Island. On this policy on Hansen's disease during the American rule, Kamikawa stated that a "serious problem" has occurred as improved patients go home and then relapse into the disease" (Yutaka Kamikawa, "Leprosy in the South Seas," *Treatment and Prescription*, No. 280, June, 1943).

In Dutch East Indies, i.e., Indonesia, there is a statement about the immigrants from Java Island brought in for labor by the Japanese military: "they are in a state of confusion, even including some 'leprosy patients.'" This is included in the "Survey

Report of the Navy-Occupied Territories of the South" written by Major Toshizo Hori, an accounting officer of the Navy in the Southern Administrative Division, who visited and surveyed the Navy-occupied territories between February 28 and April 19, 1944. (The original volume is in the Library of the National Institute for Defense Studies, Defense Agency.)

3. Pacific Regions

In 1919, Japan was given the League of Nations' mandate to rule Mariana, Marshall, Palau, and Caroline Islands, virtually colonizing them. The South Seas Agency opened a small-scale sanatorium for Hansen's disease on Jaluit Island in 1928, another on Saipan Island in 1929, another on Yap Island in 1930, and another on Palau Island in 1931. After December 1941, when the war began with the United States and the United Kingdom, Japan expanded its occupation of Pacific island groups. On August 25, 1942, the Navy occupied the Nauru Island, which was under the mandated rule of Australia. There had been a leper station that had been established by the Nauru Administrative Government on the island, where 39 patients had been found when Japan occupied the island. Nauru's administrative officer Mark Ridgeway gave the following shocking testimony in 1948, after the war had ended: a year after the occupation began, he said, "the Japanese military pushed them onto a boat, sent the boat away to sea, and destroyed it by gunfire. There was absolutely no survivor" (NEWSITEMS, *International Journal of Leprosy*, Vol. 16, No. 4, 1948). Similar reports were made in a joint research paper, published in 1952, by H.W. Wade of the Leonard Wood Memorial Research Center and Vladimir Ledowsky, a government medical officer of Nauru (H.W. Wade and Vladimir Ledowsky, "The Leprosy Epidemic at Nauru: A Review with Date on the Status since 1937, *International Journal of Leprosy*, Vol. 20, No. 1, 1952).

There is no doubt that, in the summer of 1943, patients of Hansen's disease on Nauru Island were massacred by the Japanese military. This Nauru incident should be remembered as a consequence of the segregation policy in an occupied territory.

29. Case of I-Star Hotel Denying Accommodation #18

A. Deeply Rooted Discrimination and Prejudice

When the denial of an accommodation was reported, the society voiced a shout of deep anger. However, when, upon the hotel's apology as a matter of form, residents (patients) rejected the act, accusing the hotel of "lack of sincere regrets," then, the tide was turned drastically. A deluge of telephone calls and letters of slander were made and written, not only to the prefecture but also to the (residents') self-governing association, etc. When the news reported that I-Star would leave its "hotel business," a flood of angry phone calls were made, and letters were written in protest again. This series of incidents once again painfully reminded us of the lack of understanding on the part of the general public toward Hansen's disease and the depth of the prejudice and disrespect toward former patients. In this I-Star incident, the prefecture took a very resolute attitude, so the problem became well-known; however, one can only imagine that there must be hundreds of other similar incidents that are not made known.

As is commonly known now, the decision of the Kumamoto District Court points out that discrimination and prejudice against patients of Hansen's disease, which exist even today, had their starting point in the through enforcement of compulsory segregation through Leprosy-Free Prefecture Campaigns carried out massively across the country from about 1929 to the end of the war. It goes without saying that the propagation and distribution of erroneous medical views significantly contributed to the discrimination and prejudice, also. One characteristic in the history of the problems involving Hansen's disease is that not only non-experts but also experts, particularly the experts centrally positioned in the medical science and treatment of Hansen's disease in the country, actively and intentionally propagated and distributed their erroneous views, against the world's trend, in order to thoroughly defend the absolute segregation policy. The responsibility of local governments cannot be ignored, either, because, after the war, it was local health centers, in place of the Public Health Police, who worked on the frontline of the "Leprosy-Free Prefecture" campaigns. By this, these campaigns reached far, fueled by efforts of doctors and public district nurses. The "goodwill" of these people brought "all-patients confinement" into action The responsibility of the religious community cannot be forgotten, either. After the war, various religions and denominations, released from the government control, competed to get into sanatoria and began working on "teaching of comforting religion" and "comforting doctrines," based on churches, etc. set up within the sanatoria. They taught the residents that the segregated life at the sanatoria was their "destiny, fate," which should be accepted; they taught the residents to seek salvation to come in the other world instead of salvation in this world.

B. Double Discrimination Structure

Behind the external discriminatory action of the hotel lies a wide and serious discriminatory structure of the society. It can be concluded that the existence and the fact of the many protests made to the self-governing association, etc. *are* the essence of the real problem to be dealt with directly. As long as recovered patients live passively and quietly as beings to be pitied, the society shows sympathy and understanding. But when they try to take a stand against the powers under which they are enduring, the society shows no understanding for them. Perhaps this should be called discrimination and prejudice without sense of discrimination. Of course, this "discrimination and prejudice without sense of discrimination" is also a strategic product of "Leprosy-Free Prefecture" campaigns, etc., since "sympathy" and "society cleansing" (ethnic cleansing) were the theory behind the campaigns. Media reports on Hansen's disease also contain much of the "sympathy" component; they are not playing their role of posing questions.

It is the responsibility of justice and legal experts to defeat this "sympathy" theory from the viewpoint of the theory of human rights. However, justice and legal experts have not yet fulfilled this responsibility. The clear deviation from even the "(New) Leprosy Prevention Law" as seen in the Fujimoto Incident powerfully indicates that justice community and the legal community were both inflicted with discrimination and prejudice against Hansen's disease. The problem awareness that the legal experts have contributed considerably to the neglect of the problems of discrimination and prejudice is not seen even now. The awareness among lawyers and bar associations as a whole is even slower than that of the government administration.

C. Recurrence Prevention

It is necessary to systematically and continuously take countermeasures that are comprehensive and scientific, and especially from the standpoint of those who are discriminated against, based on such characteristics accordingly as seen in the discrimination and prejudice against Hansen's disease, as generated through the government policy. The following is remarks in "Responses of the Governor of Kumamoto Prefecture," dated November 11, 2004, in response to the opinion inquiry submitted by this Verification Committee.

(1) Education of human-right awareness must be repeatedly and widely carried out.
(2) It is necessary to have the self-awareness that the human-rights problem is everyone's own problem, not someone else's, without shifting responsibilities to others.
(3) There are cases in which prejudice, once formed, cannot be wiped away simply

by receiving correct knowledge; it is necessary then to have exchange and communication (empathy) as human beings, sharing with one another.

(4) In order to stop the chain reaction of prejudice from one generation to another, education must be carried out with an emphasis on the young generation.

These are all indispensable points to remember in further educational activities. Currently, through sanatorium visits, circles of exchange are spreading in many places. Also, superior practical education in elementary and secondary educational institutions is accomplishing many great things in various places.

However, elementary and secondary educational institutions are not sufficient as far as accurate medical teaching of adults by experts concerning Hansen's disease is concerned. Given that in the past Leprosy-Free Prefecture Campaigns were carried out by local health centers working on the frontline, it is naturally the responsibility of the health centers to popularize correct medical knowledge, but the reality is that it is far from being sufficient. We strongly urge that the involvement of the government and local municipalities be increased.

There is also a need to make legislation concerning a human rights redress system. Governor Shiotani of Kumamoto gave the following answer to a general question asked in the Prefecture Assembly of Kumamoto held on February 25, 2004: "What I felt through these events is the importance of education-of course, this is true-, and I think that legislation must be made as soon as possible for an effective system of human rights redress, for those who suffered damage by infringements of their human rights."

From the viewpoint that this hotel incident was a serious violation of human rights, the prefecture of Kumamoto persisted in maintaining its resolute stand consistently over the accommodation-denial problem. This same prefecture, more than any other, actively worked to eliminate discrimination and prejudice against Hansen's disease. The fact is that this prefecture is the one stressing the need for immediate legislation for an effective system of human rights redress. The national government must accept this fact seriously. There are many different opinions on the "Human Rights Protection Bill," which was frustrated, but some agreement should be reached very soon as it is necessary toward legislation for an appropriate system to protect human rights.

30. Recommendations for Prevention of Recurrence #19

A. Legislating Various Rights of Patients and Human Subjects

One crucial key for preventing recurrence of human-rights violation under policies of public health, etc. is to legislate various rights of patients and human subjects. New legislation is necessary for the following reasons: currently there is no legislation protecting the rights of patients; there is no legislation protecting human subjects of clinical research in general; the current Infectious Diseases Prevention and Medical Care Law does not stipulate the basic principles concerning prevention and medical care of infectious diseases (such as the principle of voluntary consultation, principle of minimal mandatory measures, principle of not using classification with a term for illness that may cause discrimination and prejudice). Neither current laws nor the operation of current systems are sufficient.

There are three main points among the specific contents of this recommendation. The first is to make stipulations centered on the following eight items: (1) right to receive best possible medical care and at-home medical care; (2) right to self-determination concerning medical care and the right to "informed consent"; (3) right to obtain medical-care information; (4) right not to be made a human subject for improper human experiment or improper medical or scientific research, not based on the principles of medical and scientific research; (5) right to refuse sterilization or abortion; (6) right not to have one's freedom limited improperly; (7) right not to be put into forced labor; and (8) right to return to the society. The second point is the stipulation of various principles of prevention and medical care of infectious diseases, such as (1) the principle of voluntary consultation, (2) the principle of minimal mandatory measures, and (3) the principle of not using classification with a term for illness that may cause discrimination and prejudice. The third point is to stipulate the government responsibilities and their policies in order to prevent prejudice and discrimination against patients and families.

The government's involvement, including financial backing, in measures that are comprehensive and scientific, and above all from the standpoint of those who are discriminated against, based on the characteristics seen in the discrimination and prejudice against Hansen's disease, is still shallow and poor. Can the government justifiably fulfill its responsibility simply by tossing it to local governments, etc.? Under such circumstances, it will be quite effective in controlling discrimination and prejudice to clearly define fundamental plans for preventing discrimination and prejudice not just against Hansen's disease but also any discrimination and prejudice on the basis of any illness and to clarify by legislation the responsibilities of the government and others for the implementation of such plans. It will enormously encourage those who are being discriminated against on the basis of illness.

B. Constructing a System to Guarantee Scientific Propriety and Transparency in Policy-Making Process

The self-righteous and unscientific views of the so-called "authorities" had powerful influence on the erroneous government policy on Hansen's disease. In order to prevent recurrence, it is particularly important that government policies on public health, etc. be made on the basis of updated, fair, and scientific knowledge. Further, making public-health policies by a majority rule is accompanied by an inherit problem as was pointed out by the decision of the Kumamoto District Court that the protection of human rights of a minority may be threatened. To avoid it, it is essential to respect certain rights, such as the right of the involved party (a person whose human rights may be violated) in an early stage of policy making process to call possible problems to attention and thrash them out, and to participate as a committee member from the initial stage of drafting and preparing a bill. This point too is not included in current laws or current systems; new legislation is considered necessary.

There are three main points among the specific contents of this recommendation. The first is to ensure that the following five points are observed in making policies on public health, etc.: (1) to absolutely respect the Constitution and the international laws of human rights; (2) to make basic points and principles be stipulated as legislative matters; (3) to make recommendations for expert committee members based on systematic recommendations of experts' groups and professional organizations; (4) to have a patient as a committee member; and (5) to have a committee, not administrative bureau, draft and prepare reports, statements, outlines, etc. The second point is to open up simultaneously to the public the process of making national policies on public health, etc. to make the process transparent and to provide necessary information to the people. The third point is to have legislation that will legally stipulate measures and procedures for making, revising and repealing government policies on public health, etc. in order to ensure that patients' participation and opinions are well-respected.

C. Developing a System to Protect Human Rights

We have long overlooked, and neglected very serious and large-scale violation of human rights against patients of Hansen's disease, etc. In order to prevent recurrence, it is an urgent challenge to protect, individually and specifically, the rights of patients and human subjects in public health, etc., according to the reality of their treatment and sanatorium living. It is also an urgent challenge to create a system to protect human rights, a system that is quick and easy for patients to use. In her response to a general question posed in the Prefecture Assembly of Kumamoto, Governor Shiotani said that through the I-Star Hotel Accommodation Denial Incident, she felt "that legislation must be made as soon as possible for an effective system of human rights redress, for those who suffered damage by infringements of their human rights." This response eloquently speaks of this need more than anything else.

There are three main points among the specific contents of this recommendation. The first is to publicly issue the rights of patients, etc. and make efforts to make them known to the general public. It is a measure to accompany "Legislating Various Rights of Patients and Human Subjects" mentioned in the previous section. This is because legislating human rights may not do anything and the rights may be buried unless they are taught widely and thoroughly to the general public.

The second point is to newly establish a system of a "committee on patients' rights" (tentative name) to protect various rights of patients and others. Considering the need of immediate materialization of a human-rights redress system that is effective for those who have suffered discrimination and prejudice on the ground of their illness, it is desirable to establish anew a system of "special committee on patients' rights" as a specialized committee to protect "patients' rights." Under a new "human-rights committee" system based on the "Paris Agreement," such a dedicated committee system is expected to play a big role.

The third point is to create a national human-rights institution based on the "Paris Principles." The "Human Rights Protection Bill" was frustrated with much criticism, but this does not by any means reduce the need to create a national human-rights institution based on the "Paris Principles." No one objects to the need to create such an institution; we hope that agreement can be reached promptly toward the creation of a better national human-rights institution.

D. Points to Remember in Compiling a Budget in Public Health, etc.

The fact that the post-war "Leprosy Prevention Law" was not repealed until 1996-a delay of at least 30 years-even after it was already unconstitutional by 1960 at the latest-is closely related to a financial factor. In budgetary negotiations between the Ministry of Health and Welfare and the Ministry of Finance, the Ministry of Health and Welfare could not propose the repeal of the Prevention Law because this law was the basis for compulsory segregation, which in turn formed a legal basis for the Ministry to appropriate funds for improving the living conditions of patients in national sanatoria for Hansen's disease. Time elapsed. Even to resident patients, repealing the Prevention Law appeared to nullify any accomplishment in the improvement of their living conditions. They could not help hesitating when it came to involvement in the repeal of the law. Looking back at this history, it is absolutely essential to define some new principles for compiling a budget based on respect for human dignity and human rights in order to prevent recurrence in the field of public health, etc.

We should request that the Ministry of Finance define new principles for compiling a budget so that, for the purpose of public health, efforts will be made to appropriate funds even if there are no binding elements of the law.

E. Remedy to and Recovery from Damage

As evident from the "Survey Report of the Reality of Damage concerning Hansen's Disease Problem" of this Verification Committee, damage caused by the government's erroneous compulsory segregation policy on Hansen's disease is still going on today. Saving victims from such damage and helping them recover will be the best preventive measure. There are more than just a few challenges remaining concerning damage recovery from the compulsory segregation policy on Hansen's disease.

It has become an urgent task to prepare an environment and to create receiving plates for their society return, but the current situation is very insufficient. We urge strongly that local governments, etc. take detailed actions based on the actual situations as citizens participate, along with financial support of the national government. Some have pointed out that local governments need to establish "society-return support centers" (tentative name). Contribution of experts in fields related to social welfare, based on self-criticism, is also indispensable.

As for elimination of discrimination and prejudice, we have a strong request to bar associations, the media, religious communities, etc. When the residents of sanatoria for Hansen's disease stand up in protest, the society often opposes such a move and sometimes even shows enmity. In order to eliminate this "discrimination and prejudice without sense of discrimination" as soon as possible, we ask you to work together with other organizations and groups to take continual measures and to build a system to promote such efforts.

Many have pointed out that the biggest challenge which sanatorium (residents') self-governing associations and the All-Japan National Hansen's Disease Sanatoria Residents' Association are facing today is the "Problem of Design for the Future Sanatoria." On this issue, we would like to confirm and remind that "the government and the society must deeply acknowledge that they themselves are responsible for leading to the current state of affairs and take actions with sufficient understanding of the responsibility." Also, permanent resting places must be secured for those ashes now placed in charnel houses.

Remedy and recovery must be carried out quickly and properly for other types of damage in the field of public health, also. This is too the best preventive measure.

F. Propagation of Accurate Medical Knowledge

In order to build a society where patients of infectious diseases are not thrown out as dangerous beings and patients and families of hereditary ailments are not discriminated against as human beings with inferior genes, each one of us must have accurate medical knowledge. From this point of view, one thing to focus our attention is the actions of the local health centers, etc. This is because in the past the health centers were working on the frontline of "Leprosy-Free Prefecture Campaigns." Given this fact, it is natural responsibility that the health centers take on the central role of wiping out erroneous beliefs and actively teaching and propagating accurate medical knowledge. We would like to strongly urge that the government and municipalities get more involved in this regard. Some physical education textbooks continue to use the term "leprosy," but this too should be changed promptly.

There are three main points among the specific contents of this recommendation. It is true that for some acute infectious diseases, mandatory isolation may be the only option. However, even in such cases, limitation of human rights of the patients should be kept minimal, and best possible medical care must be guaranteed to the patients. Because chronic infectious diseases are not as contagious as acute infectious diseases, and because isolation is impossible without seriously violating the basic human rights of the patients, in general the patients shall not be isolated. This is the first point.

What the erroneous Japanese absolute segregation policy on Hansen's disease is teaching us is that the medical and clinical community, which promoted and implemented this policy, decidedly lacked the perspective of the patients and their families. This perspective must be ensured to be respected. This is the second point. The third point is that it is urgent that legislation be made to establish "patients' rights" such as informed consent and second opinion so that the patients and families can choose for themselves what the best treatment is for them.

In Japan, medical associations are merely voluntary organizations; the Physicians' Law and other laws do not allow self-government of medical associations. Ethical standards of medical associations are also private. If the term "expert" means someone who is guaranteed independence and autonomy deserved by those with expertise, then Japanese doctors are not experts. The authority to punish physicians belongs to the Minister of Health, Labour and Welfare. In contrast, a ground for punishment is limited to "criminal cases penalized by at least a fine." This is in no comparison with public employees. Should the government be the ones in charge of control and sanctuary for doctors? The answer should be clear. In order to ensure the establishment of their expertise in the health-care profession and to improve occupational ethics, they must depart from the nationally managed system and switch to a "self-governing system." Many countries already use such a "self-governing system" in their efforts to establish expertise and to improve occupational ethics.

We have already presented a detailed analysis to show that one of the main reasons for the Japanese erroneous compulsory segregation policy maintained for so long was the fact that Japan deviated significantly from the trends of international conferences. To build a system which will never allow such a departure in the field of public health will also be quite effective in preventing recurrence.

G. Thorough Education of Human Rights

The importance of having accurate medical knowledge cannot be over-emphasized. However, regardless of how popularly accurate medical knowledge is propagated, discrimination and prejudice against diseases will never go away unless we thoroughly understand and take a position that discrimination on the basis of a disease-whether it is infectious or hereditary-can never be tolerated.

There are two main points among the specific contents of this recommendation. First, more educational activities should be carried out. One thing to pay attention to is the "Responses of the Governor of Kumamoto Prefecture," dated November 11, 2004, in response to the opinion inquiry submitted by this Verification Committee. It contains the following four remarks.

(1) Education of human-right awareness must be repeatedly and widely carried out.

(2) It is necessary to have the self-awareness that the human-rights problem is everyone's own problem, not someone else's, without shifting responsibilities to others.

(3) There are cases in which prejudice, once formed, cannot be wiped away simply by receiving correct knowledge; it is necessary then to have exchange and communication (empathy) as human beings, sharing with one another.

(4) In order to stop the chain reaction of prejudice from one generation to another, education must be carried out with an emphasis on the young generation.

Each is an indispensable factor, but among them two things stand out as being especially crucial. They are the need for "exchange and communication (empathy) as human beings" and the need for "education with an emphasis on the young generation." As often said, "A picture is worth a thousand words"; circles of communication are spreading in many places through visits to sanatoria. It is also reported that superior practice of education in elementary and secondary educational institutions is accomplishing many great things in various places. We hope that this type of work will continue and be expanded, along with cooperation between the national government and local municipalities, and between municipalities.

The second point is solid education of human rights. We would like to touch on advanced education, particularly the need to establish solid education of human rights in medical schools and related departments. The current situation is far from being satisfactory. We must also remember to provide education of human rights to employees and staff members working in medical facilities and welfare facilities. Why did those workers become the means to carry out human-rights violation? Including this point, fundamental curriculum reforms are needed in a timely manner.

H. Preservation and Display of Resources

While discrimination and prejudice against patients of Hansen's disease and their families as well as recovered patients have been caused by the erroneous government policy, nevertheless the government is not the only ones responsible for the discrimination and prejudice. It was the local municipalities that actually carried out the segregation, and it was the people who kicked out the patients out of their regions. In order to prevent the recurrence of such violation of human rights, we must examine the responsibilities, not only of the government, but also of local municipalities and of the people themselves. In doing so, it is essential to consult resources stored in government agencies including the Ministry of Health, Labour and Welfare, municipalities, sanatoria for Hansen's disease, and self-governing associations of residents of sanatoria for Hansen's disease. It is desired that we pursue and discover truths concerning the segregation policy, including everything from the government level to the local level, and reflect the resulting findings in the educating of the society in order to prevent recurrence.

Hence, efforts to preserve such historical facilities as symbolizing the erroneous compulsory segregation policy, and to display them publicly are also crucial challenges from the standpoint of recurrence prevention.

I. Establishment of the "Roadmap Committee" (tentative name)

Recommendations for preventing recurrence presented by this Verification Committee are multi-faceted. Some require legislation, and others can be carried out by improved operation. Time required also varies, from short-term projects to mid- to long-term work. Administratively speaking, some will cut into walls of "vertical sectionalism" and "horizontal sectionalism," which are feared to block the implementation of our recommendations significantly. Hence, we also recommend that the government on its own responsibility establish an independent third party body "Roadmap Committee" (tentative name), similar to this Verification Committee, in order to carry out these specific recommendations. The contemplated mechanism here is for this third-party body by itself to define "action plans," etc. for specific implementation of our recommendations, to request the execution of these plans to the government and local municipalities as needed, and to monitor their progress. The proposals of this Verification Committee also contain those for bar associations, the media, religious community, and various other communities. It will also be one of the mandates of the "Roadmap Committee" that the committee meets with these organizations for discussions so that they can establish an environment for their own self-initiated, voluntary implementation.

Specific contents of this recommendation concerning the establishment of a

"Roadmap Committee" are as follows:

First, the committee should be an independent third-party body just as this Verification Committee.

Second, the committee should define "action plans," etc. for specific implementation of the recommendations to prevent recurrence presented by this Verification Committee, to request the execution of these plans to the government and local municipalities as needed, and to monitor their progress. These are the main tasks of the committee.

Third, the committee should consist of members that include representatives from this Verification Committee, patients of Hansen's disease and/or former patients, patients and/or former patients of another field related to public health, physicians, lawyers, those with scholarly experience, the media, educators, etc.

Fourth, the committee should have an secretariat office independent of the government, etc., just as this Verification Committee does, and this office should carry out all secretariat work, drafting and preparing of documents and materials, and other related tasks.

Fifth, the government should provide funds necessary for the operation and activities of this committee.

Finally, sixth, the government, etc. shall sincerely and faithfully implement the "actions plans," etc. established by the committee and report the implementation progress to the committee.

Final Report of the Verification Committee Concerning Hansen's Disease Problem

(Summary Version)

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