

Hansen's Disease and Human Rights Activism in Postwar Japan: The Life of Usami Osamu (1926-2018)

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Precis: A translation of an oral autobiography of the life of Usami Osamu (1926-2018), the human rights activist and lead plaintiff in the lawsuit brought, and won in 2001, by men and women whose lives were taken away under Japan's Hansen's Disease (leprosy) absolute lifetime quarantine policy, in effect until 1996, who passed away on April 10th. A portion of his ashes will remain at Nagashima Aiseien National Hansen's Disease Sanatorium in Okayama Prefecture where he lived for almost seventy years and another portion will be placed in his family grave in Aichi prefecture, the reunion with the parents he struggled for throughout his life.



Usami Osamu (photo by Lowell Brown, 2007)

The Japanese human rights activist Usami Osamu passed away on April 10, 2018, at the age of 91, at Nagashima Aiseien National Hansen's Disease Sanatorium, on an island in the Inland Sea in Okayama Prefecture, where

he had lived since he was put under quarantine for Hansen's Disease (leprosy) in 1949. His national exposure came seventeen years ago, when he appeared on the front page of every Japanese daily newspaper shaking the hand of Prime Minister Koizumi Jun'ichirō as he and his fellow plaintiffs began a hunger strike in front of the Prime Minister's official residence on May 23, 2001, in an effort to appeal to him to accept the Kumamoto District Court's decision in their favor in their lawsuit to restore the civil rights cruelly taken from everyone diagnosed with Hansen's Disease in Japan long after effective antibiotics rendered the disease treatable. In the days that followed, the government apologized, media and public attention began to listen to the stories of the men and women whose lives had been hidden for decades, and many, but not Usami, returned to their hometowns as elderly men and women, for the first time. In the decade that followed, until he slipped away into dementia, Usami travelled widely around Japan and abroad, to Brazil and India for International Leprosy Congresses, to Myanmar to speak in schools, and to Norway to the hospital where the physician Armauer Hansen first identified the pathogen *Mycobacterium leprae* in 1871. Speaking to schools, lawyers associations, civil and human rights activists, and medical associations, he was a critical witness to what happened to him and his fellow recoverees of this heavily stigmatized but thoroughly treatable disease.¹

In fact, as he recounts in the translated oral history which follows, Usami's activism began as soon as he arrived at Aiseien and had his first contentious encounter with its director,

Masuda Kensuke (1876-1964), whose domination of Hansen Disease policy in Japan and insistence on lifelong quarantine and sterilization of men long after it was outside global norms remains divisive to this day. Over the years leading up to the lawsuit, it took a number of forms: leadership in the Aiseien residents' self-government association as well as the All-Japan Hansen's Disease Sanatorium Residents Association (Zenryōkyō), membership in the Japan Communist Party which was allowed to register voters at Aiseien beginning in the early 1950s, collection of a large library related to all aspects of Japanese society's mistreatment and dehumanization of those diagnosed with the disease, and the single-handed curation of the treasured possessions of his friends and the cast-off equipment of the hospital as a remarkable museum housed, ironically, in the "Imperial Bequest Hall" built to honor the 2,600th anniversary of the Imperial Nation. (The stamp of the Imperial Household is found not just in the Taishō Empress's portrait in Usami's museum but in stone monuments at Aiseien and most all of the thirteen Japanese national leprosaria (plus two established in the colonies) carved with her famous *tanka*—directed to Mitsuda and not the quarantined—calling on him to "comfort them in my stead.")

Usami was born in the western part of Aichi prefecture—the name of the city, Tsushima, was, of course, kept secret until recently—on June 29, 1926, and arrived at Aiseien in early 1949, his dreams of education and a "normal" life as a "healthy" citizen of postwar Japan disrupted. He was unusual in refusing ever to use a "leprosarium name" in place of his birth name and he was deeply hurt by the way his two brothers hid his existence from their children and banned him from paying his respects at the family grave. Finally, in 2009, thanks to the intervention of his loyal friend and supporter Namba Satsuya, he was able to meet his eldest nephew, who promised to place his ashes alongside his parents' in the family

grave when the time came. His nephew did honor that promise at Usami's funeral, which was held at Aiseien two days after his death, but the local newspaper also reported that a portion of Usami's ashes will remain in Banreizan, the community mausoleum at Aiseien, alongside his friends who went on ahead after lifetimes of building a community of hopefulness and friendship in the midst of cruel policies, illness and stigma.² He was determined that the lives none of them chose but which they made together will not be erased or forgotten.³

The following "Sunlight to the Depths of the Sea" is an abridged translation of the oral history Usami dictated in 2007, when he was past 80 and complications of diabetes had severely limited his vision, and published that year as the first chapter in a collection of his lectures, affidavits, and court testimony entitled *Nomichi no Kusa: Hansen-byō Zettai Kakuri Seisaku ni Mamukatta 70-nen* (Grass on wild paths: 70 years of facing down the policy of absolute quarantine for Hansen's Disease) (Mizuho Shuppan, 2007).

At the First Examination, Director Mitsuda Kensuke said "Usami, get the hell out!"

I believed that if I came here, to Nagashima Aiseien, I could receive injections of Promin right away.⁴ I was 23 when I came to Aiseien. It was April 27, 1949 (Shōwa 24). It was about thirteen days later that the director, Mitsuda Kensuke, gave me my first examination. It had been a long wait, a long-held desire, and I was glad he was going to see me. I almost ran to the medical ward, telling myself that my Hansen's Disease was going to be healed. Expecting an injection, I presented myself to Dr. Mitsuda.

Instead I was asked, "Why didn't you come here sooner? What is it you don't like about this place?"

I answered, "Even though this is a national sanatorium, food, clothing, housing, and hygiene conditions are all poor. Four married couples, eight people are sleeping in a twelve-and-a-half mat room, without so much as a curtain. This is inhumane. Even pigs would fight in such conditions."

Mitsuda shouted back at me, "If you have complaints, then get the hell out now!" He was saying he would issue a discharge order, while enforcing the policy of forced incarceration.

I had no home to return to and no other place to go and so this was a problem, but, figuring that if he was telling me to get out, I had no other choice, I took off running. Soon I was being chased by a nurse.

"Mr. Usaaaami, wait! Come back!"

He grabbed my sleeve and took me back to the medical ward. This time it was a different doctor.

"Sir, are you a communist?" he barked at me.

"Nihilist," I answered.

"My, don't you have a quick tongue..." he said. "You have nowhere to go now, do you? The Director explained the situation to me. You stay here, Usami."

I breathed a sigh of relief. Later I learned that this doctor's name was Namba Masashi and he was a graduate of Okayama University.

This incident had quite an impact on me.

The Reality of Director Mitsuda, "Savior-Father of the Lepers"

Dr. Mitsuda Kensuke was such a god-like figure that he was known as "Savior-Father of the Lepers" and "the Dr. Schweitzer of Japan," but, as you can see from his attitude toward me, he

was no doctor who saved Hansen's Disease patients. It is better to say that he was a criminal who deceived the medical world and the nation into seeking the elimination of the disease through his policy of lifelong quarantine, denying patients their human rights.

In 1916, when he was director of Zenshō Hospital, Mitsuda implemented the policy of sterilization by vasectomy for male patients who wanted to marry.

He was the one who declared that, "Because leprosy is a fiercely contagious disease that is inherited, it will be exterminated by forcibly quarantining patients from ordinary society. They must not produce descendants. Make that the law. Put them in shackles and force them into quarantine." That was his testimony before Health Committee of the House of Representatives of the Diet on November 8, 1951. He had the government build incarceration facilities under the name "National Leprosaria" on islands and in remote areas and initiated the forced incarceration of Hansen's Disease patients. Patients surely thought that if they went to a national sanatorium, their disease would be cured. If you hear the word sanatorium, you surely think of a hospital, but on arrival at the sanatoria, patients were put in a Kresol disinfectant bath and then made to sleep like sardines in a cramped room. Patients with more severe cases of the disease were left to wait for death. Even if they got sick, they were not given adequate treatment. Less severely affected patients were made to do manual labor or provide care for the worse off.

My *senpai*, the patients admitted before me, suffered horrendous aftereffects of heavy labor and malnutrition and many died. Conditions were cruel at that time. It was no way for human beings to be treated.

It was as the first director of Nagashima Aiseien that Dr. Mitsuda ordered patients to do

heavy manual labor. “Here will be your paradise, so with your own strength, clear away the mountains and build roads and houses. That is your mutual aid, your work to repay all the blessings you have received.”

Some could not stand the terrible conditions and escaped but drowned trying to swim across the sea. The ones who failed in their escapes and were captured were locked up in the prison ward.

One doctor spoke up in the Japan Leprosy Research Association. This was Dr. Ogasawara Noboru, a native of Jimokuji Town, Ama County, Aichi Prefecture, and a graduate of the medical department of Kyoto Imperial University. He stuck to his academic understanding: “Leprosy can be treated. Its contagiousness is not strong. Forced quarantine is not necessary.” He did not give up. I respect him.

In 1934, Dr. Ogasawara lectured on “the essence of the extreme virulence of leprosy,” stressing “the weakness of its infectiousness,” but Mitsuda’s majority did not accept what he was arguing and, ignoring the progress being made by the world medical community, asserted that “leprosy is hereditary and terrifying infectious.”

Forty-two years earlier, in 1873, the Norwegian bacteriologist Armauer Hansen had discovered the leprosy bacterium. Then, in 1943, the effectiveness of the drug called Promin in treating the disease was proven in the U.S.

Unbelievably, at the fifteenth meeting of the Japan Leprosy Research Association, the Mitsuda majority proposed a referendum that “Dr. Ogasawara Noboru be expelled from Kyoto Imperial University as a national nuisance” and sent it on to the university president. The university, however, let him continue to research and treat Hansen’s Disease in the dermatology department until he reached retirement age.

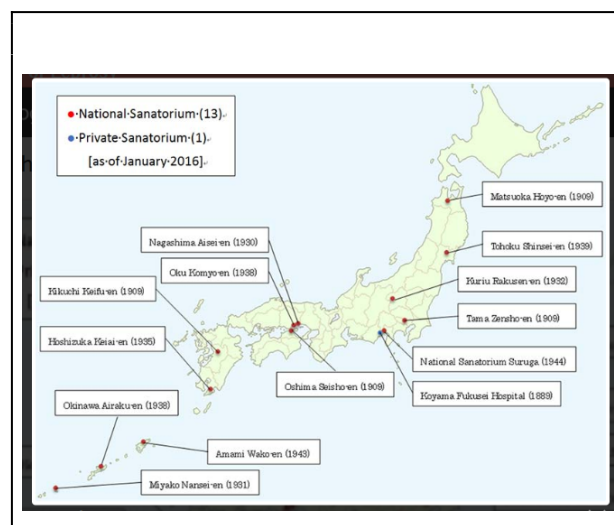
It was terrible, unimaginably terrible.

After Dr. Ogasawara’s thesis was suppressed, medicine in Japan lost its way and merged with power, planting mistaken ideas like prejudice and discrimination in the people of the nation. Dr. Mitsuda and his followers were the ones who destroyed the lives and the fates of the patients and their families.

When revisions to the “Leprosy Prevention Law” were debated in the Diet in 1951, Dr. Mitsuda testified that “leprosy patients must be uprooted, hauled away in shackles, and forcibly quarantined” and that “escape must be criminalized and escapees put in prison.”

Young doctors who did not know what Mitsuda was really like adored him and carried out his policy of forced quarantine. You can see this if you read Ogawa Masako’s *Spring on a Small Island*, which was also made into a movie.⁵

My comrades and I built a movement to rectify the ignoring of our human rights, reform the country’s and Dr. Mitsuda’s ways of doing things, and live like human beings. Some of our fellow patients, however, believed that “if Director Mitsuda is so disagreeable to you, why don’t you leave? If we oppose the state and it cancels the sanatorium budget and chases us out, we’d have nowhere to go. We’d die in a ditch somewhere.” It’s a shame.



Japan's thirteen national and one remaining private Hansen's Disease Sanatoria (2016). (Source)

An Attitude Visitors Cannot Believe Either

When I speak to visitors to the leprosarium about the realities of life here, they have a hard time believing that this could happen and they always question me on it.

To convey the truth of history to my fellow citizens, individually and in groups, and to build a society with no prejudice or discrimination, it is necessary to do more than pray and thank them for their charity. To this end, I have been creating a "Hansen's Disease Museum," preserving objects used in daily life here in the leprosarium and collecting books and other materials.⁶ I've been working on it for eighteen years and I've collected more than 6,500 books.



長島愛生園内の資料館（恩賜記念館）の中に立つ
＝2001年10月25日、朝日新聞・高波淳氏撮影

Usami stands in the museum he created at Aiseien, October 2001 (photo reprinted in *Nomichi no Kusa*)

just toward people who have had Hansen's Disease but also toward those with AIDS and *dōwa mondai* (against those defined as *Buraku* "outcastes") and so on. I want to discern these realities and make them right. I want discrimination and prejudice to be eliminated as soon as possible. How children develop images is a serious problem. I can sense the same factors at work deep inside me.

Anyway, soon after I arrived at Aiseien, I was already labelled "a marked man."

Strengthening My Resolve for Everyone's Sake

How did I keep my spirits up?

What I learned from my studies is that Hansen's Disease has its own history within the long, long history of humanity and that, though medicine lagged in its treatment of Hansen's Disease in the ancient and medieval periods, great strides were made in Europe and America in modern times to conquer the disease and to begin to eliminate prejudice towards the disease in society. In Japan, however, advances in medical knowledge in the world continued to be hidden and the policy of absolute lifelong quarantine in the law lasted until just ten years ago. Why? There were more causes than I can say here, but the main cause was the mistaken ideas and practices of the doctors. This must not be overlooked.

My talk today has ended up being about my relationship with Director Mitsuda but for decades I have wanted to break down the taboos and the tendencies that turn people into yes men for the "Mitsuda-ism" which forced out doctors who were working to advance medicine and prevented us from being treated as human beings. I have never wavered in my determination.

Real discrimination in society is directed not

When I became an officer in the residents' self-

government, my concern to put everyone's collective needs before my own grew stronger.

As someone who does not talk about himself, I never felt that this was odd or unnatural, just as anyone who does not want to recall a bitter past praises the one who devotes himself to society.

My friends here at Aiseien, as well as friends and acquaintances from the outside world often say, "Usami-san, we want to hear about you yourself..."

I answer this way: "Let's skip my story. We must right the injustice of the leprosy policy of the Japanese state since the Meiji period in order to calm the anguish of my friends here who cry themselves to sleep because of discrimination and those deceased patients who cannot return to their home villages even as ashes." I continue the struggle.

Extraterritoriality in the Leprosarium

I was incarcerated at Nagashima Aiseien National Leprosarium on April 27, 1949. I was 23 years old. Aiseien is on an otherwise uninhabited island in the Inland Sea, in Oku Town (now Setouchi City), Okayama Prefecture.

It had been four years since the conclusion of Japan's War of Aggression which forced the Japanese people and the peoples of Asia to taste the unbearable. Two years had passed since the Constitution had been put in place, coming out of contrition for that war.

With its pillars of the renunciation of war, fundamental human rights, and democracy, the new constitution established that men and women are not to discriminate against one another and that all Japanese people are equal under the law. However, the fundamental human rights of Hansen's Disease patients and

their families were still not recognized, even in the postwar period, under the new constitution.

The law did not prevail in the leprosarium. There was a prison inside the leprosarium, which is, after all, a hospital. Who was put in there? Patients who challenged the Director. The Director had what was called "the authority to detain and discipline." There were no courts. This was part of the authority of his position. It was finally abolished in 1953.

There was a prison here on this island. Hard to believe, isn't it?⁷

I've Been an Officer for a Total of Fifty Years

I became the representative of District 1 of the council of the residents' self-government for district one two years after I arrived at Aiseien and I have continued in that position for fifty years. Apparently, it was hard to find officers for the residents' self-government because the patients who arrived before me were elderly and had severe effects of the disease. I was brought into the self-government because I was young and eager to be useful to my fellow patients.

People who come to visit Aiseien often say, "what beautiful scenery... like a resort..." and they may be right, but that is because conditions here have improved greatly. When I arrived, it was a sanatorium in name only. Living conditions were terrible. We were not treated as human beings. Everyone was just waiting to die.

We devoted our full efforts to having the 1931 Leprosy Prevention Law repealed as unconstitutional under the new constitution which guaranteed respect for fundamental human rights, but, unfortunately, the Leprosy Prevention Law of 1953 left the bad law as it

was, ignoring fundamental human rights and only changing the way leprosy (*rai*) was written from a Chinese character to hiragana.

However much we later worked on a movement to regain our rights, the bad law ignoring our human rights did not go away. Since Aiseien was going to be our permanent home, we changed direction to a movement focused on improving living conditions and welfare. As a result, improvements have continued until the conditions you see today, but, fundamentally, the violations of the constitution have gone on unchecked and our human dignity has not been restored. A National Hansen's Disease Sanatorium is not a place for treating a disease. It is an institution for incarceration the sick in order to exterminating the disease through their deaths. There was no way to be discharged. It was a one-way street, with U-turns forbidden.

Suicide After Suicide

Frankly, you end up losing hope for living.

There were a lot of patients who committed suicide by jumping off a cliff on the south side of the island into the sea below. I myself have stood in that place, closed my eyes, tensed my legs and shifted my weight forward... but I suppose I lacked the courage and I'm still here.

I already mentioned that there was a prison here. There was also a crematorium and a mausoleum. But no mortuary.

What happens when a resident here dies?

The officers of the residents' self-government and people who were close to the deceased accompany the body from the hospital to the crematorium, gather the firewood, and light the fire for the cremation.

What do I think happens when a body is

burning? Have I been there?

It arches, while still burning.

Someone has to force it back into shape with an iron bar, with all their might. It's the officers of the residents' self-government who do that. I've done it, too.

Until about 1975, conditions here were really terrible.

Learning About Promin

I have loved reading books since I was a child. After I contracted the disease at the age of eleven, I have bought and been absorbed in reading books about Hansen's Disease. Books like Hōjō Tamio's *Life's First Night* and *Leprosarium Miscellany*, Ogawa Masako's *Spring on a Small Island*, and Perry Burgess's *Who Walk Alone* (translated by Unami Mototada (Kaizōsha, 1941).

I must have been about twenty-two when I was reading *Readers Digest* and came across the great discovery known as "the miracle at Carville" and was absorbed completely.

The contents of the article was this: "When a sulfa drug manufactured by a German pharmaceutical company was diluted in a glucose solution and injected into patients at the Carville Sanatorium in the United States, there was substantial improvement in a short time in the most hopeless of cases. The patients are overjoyed. The name of the drug is Promin." I'll never forget reading that.

Until I read that *Reader's Digest* article, I was convinced that Hansen's Disease was incurable and that it plunged not just the sufferer but also his family and relatives into the depths of misery.

My Parents Did All They Could to Protect Me

My parents fought hard to protect me, declaring that “We’ll treat Osamu’s illness at home.” After symptoms appeared when I was in the fourth grade, they took me every week to a nearby dermatologist for injections of Chaulmoogra (*taifūshi*) oil.⁸

I told my father about Promin and he walked the streets of Nagoya, inquiring at every pharmacy, “Do you have a drug called Promin?” Why did he keep his distance from the pharmacies in our neighborhood? Because he was afraid of being ostracized if they knew. However, no pharmacy in Nagoya had the drug and none seemed to have even heard of it. Removing his shoes in the kitchen and resting his tired feet, he whispered what he had found to my mother and me, so that my younger brothers would not hear

Apparently Promin was not available in Japan.

What was there to do but give up?

As my despair deepened, my father heard that, “if we go to Tokyo, it’ll be available there.” Tokyo was still the burned-out plain left by the aerial bombings, but he went and was finally able to buy some Promin on the black market. One hundred ampoules cost 15,000 yen. Fifteen thousand yen in those days would be many times what it would in today’s money. That was the fall of 1947. A dish of curry rice cost eighty yen. A year’s tuition at Keio University cost 9,000 yen and about 8,500 yen at Waseda.

Through such strain and toil, my father finally obtained some Promin but we could not use it. Since Promin must be injected into a vein, an amateur cannot do it.

Why didn’t we ask a doctor to do the injection? We wanted to, but we couldn’t.

The reason we couldn’t ask a doctor to do the

injection was that the local police, government, and populace were united in uprooting every last Hansen’s Disease patient still at home and forcibly quarantining them in the leprosaria. Doctors had been directed to report any contact with a patient to the health authorities.

I Choose the Path of Promin Injections at a Leprosarium

After about 1936, the Japanese government intensified its forced incarceration of patients, raising the banner of “ethnic cleansing” in order to win its war of aggression.

Thus, since we could not ask a doctor to do the injection, the only choice was for my parents to do it. It did not go well. My parents both tried to inject my arm, but however much they tried, they could not find a vein. My arm was covered in blood.

The only way to be treated with Promin was to go to a leprosarium. Such was the Leprosy Prevention Law.

Having attempted suicide twice at home and not died, and having lost hope for Promin treatments at home despite the efforts my father had made to procure the miracle drug, I made up my mind that the only path left for me was to go to the leprosarium. No, it is more correct to say that my state of mind at the time was resignation, not determination. That was New Years 1949.



The main administration building at Nagashima Aiseien, a symbol of the modernity of public health as nation-building. (source).

Becoming Aware of How I Cannot Speak About the Past

Now, however, I am discovering that I run away from talking about myself and that I am unable to tell my own story.

Like memories of my hometown.

Talking about home is like rubbing salt into an open wound you might get from falling down at the school games.

I am still persecuted by the place I was born. I was told by my father that “we’ve burned all your books,” and by my mother, “Osamu, you no longer have a home to come home to. You will die here” at Aiseien, and by my older brother, “Father is dead. You are to relinquish your inheritance. Put your seal here.” My feelings for my home are not easy to discard. Sometimes tears well up when I think that I have nowhere to go home to.

Whenever I hold the one photo of my parents I have in my room, I am flooded with emotion.

At First I Could Not Contemplate Becoming a Plaintiff

The impetus for the lawsuit to prove the unconstitutionality of Japan’s Hansen’s Disease policies?

Well, in March 1996, the government finally repealed the Leprosy Prevention Law, bringing an end to the forced quarantine policy that had continued for ninety years. The Minister of Health, Kan Naoto, apologized, but the government did not recognize the truth of the wrong it had committed or its responsibility and it did not offer any reparations. It was trying to quietly bury the atrocity of the violation of our human rights by the State.

In September 1995, Shima Hiroshi had written a letter to the Kyūshū Legal Association.⁹ It said, “One would think that no one would have a deeper concern for human rights than the legal profession and yet you continue to sit back, offering no analysis or statement about the Leprosy Prevention Law.” It was this letter from Shima-san that got the attorneys to rise up and moved history towards our court battle.

The lawsuit was filed in Kumamoto District Court on March 1, 1998. On that day, the thirteen plaintiffs, including Tateyama Isao-san, Shimura Yasushi-san, and Mizoguchi Seiji-san, issued this statement:

“Is it acceptable to allow the cruel acts of State power to go unquestioned? How will the State bring healing to the isolation and regrets of we residents of the leprosaria who have no children or grandchildren? ... Through this lawsuit, we intend to make clear the history of and responsibility for the government’s Hansen’s Disease policy:

1. Why did the unprecedented abrogation of human rights in the name of the State come about, in violation of the Constitution of Japan? [We seek] to expose the truth, make clear the

responsibility of the state, and achieve reparations for damages.

2. We aim to restore every violation of human rights to their original condition, grounded on the state's responsibility.
3. We will keep the State from allowing this error to be repeated.

When these have been achieved, we intend to hold memorial services for our forebears who rest in the mausolea in the leprosaria across Japan to bring healing to their sufferings."

I was moved by their courage.

Was I late in joining the plaintiffs?

Looking back at that time, I am filled with regret. I repent for the weakness of my own heart. Even now tears of remorse come to my eyes.

When I was invited to join the plaintiffs, I hesitated, telling the group that "I don't want to repeat the divisions within the sanatorium that occurred in 1953 with the 'Leprosy Prevention Law Struggle.' But I will help." I was a coward.

In my heart I had been defeated by selfishness because I was thinking, "if I can, I want to die in my beloved hometown and rest for all eternity beside my parents. I want to share their grave."

Then, at the question-and-answer time after a lecture, I was called out by a student. "Usami-san, why aren't you a plaintiff? Isn't there a difference between what you are saying and what you are doing?" I couldn't answer him. The frankness of youth had hit my weakness on the head.

Though I had been saying "We are struggling against injustice" and "we will fight hard and not be defeated by persecution. Please support us," I was unwilling to join the plaintiffs. Later, when I had joined the legal struggle, I reflected

greatly on how weak had been my ability to grasp the profundity of fundamental human rights, human dignity, and the Constitution of Japan.

At the time, I was consoling myself and rationalizing my decision by assuring myself that the court would find the law and policies unconstitutional.

Provoked by Anger, I Join the Plaintiffs

When I talk about those days, I am still so embarrassed that my face turns red. But something happened that led me to cast off the thinking that was holding me back.

The anger that pushed me to join the plaintiffs welled up in me.

It was when I heard the contents of the draft defense the government submitted in response to the lawsuit in Kumamoto District Court.

It said: "In that the quarantine policy for leprosy patients which existed in Japan for ninety years was in no way counter to internationally accepted knowledge, nor to domestic knowledge, and since it provided for the humane treatment of patients, it was not unconstitutional." "Since vasectomies and abortions were performed with patient consent, they were not forced." "For ninety years, the government carried out its leprosy policy with charity and generosity."

When I heard the government's arguments, my blood boiled.

How could they say such things? What about the blood and the tears that had been shed? These arguments were completely unacceptable. They offered no excuse or apology to all our forebears who suffered and suffered and were now gone from this world.

What spurred my heart and mind into action

was this.

I decided to join the plaintiffs in the Kumamoto District Court case so that there would be someone from Nagashima Aiseien.

Aiseien was behind our comrades in Kyūshū, but on June 2, 1999, fourteen of us from Aiseien, including Sakurai Yūtarō, Ikeuchi Aritomo, Kawashima Tamotsu, and me, joined the plaintiffs in the fifth filing.

Later, suit was filed in Okayama District Court and I was part of the Okayama plaintiffs group, but at the time I was still not confronting directly the contents of my own heart and my knowledge of the constitution was still superficial.

A plaintiff is required to submit an affidavit to the court. For me at that time, that was the most difficult of assignments. I couldn't talk about myself. Maybe this was a peculiar kind of pride, but clearly I was weak. It was not just once or twice that the attorneys told me, "Mr. Usami, unless you speak about the facts of the damages you and your family have suffered, there will be no lawsuit."

After we won the lawsuit and the whole text of the judgment was read to me, I wept to myself for my arrogance and shabbiness of character.

When I met Mizoguchi Seiji-san in Tokyo, I apologized directly to him for my cowardice. *Sumanakatta*.

We Were Ready to Die, But We Wanted Him to Say "No Appeal"

The court system in Japan allows the losing side in a case fourteen days to appeal the judgment. If the government appealed the judgment and our legal struggle went all the way to the Supreme Court, it might end up taking ten to twenty years for the judgment to

be affirmed. If that were the case, I would probably be dead by the time the court ruled.

The deadline for appeal was May 25th and I resolved to do everything I could until the government declared it would not appeal, even if I died in the process. Every one of the plaintiffs shared these feelings.

Together with the legal teams and all of our supporters, we plaintiffs shifted our struggle to "Government, No Appeal!"

I have been alive for seventy-five years, but I don't know how to describe those ten days, those 240 hours. Anyway, we were fighting with all we had.

Images flashed before me: my father, my mother, my two suicide attempts, Director Mitsuda yelling at me to "get the hell out!," the faces of all my forebears who sleep in the mausoleum unable to return to their hometowns even as ashes... From the bottom of my heart feelings welled up: if I had died then, I would be feeling what I'm feeling now. It's great I'm alive! We are not defeated!

Determined, We Protest Even If It Costs Our Lives

As one, two, three days passed, there was an intensely strong backlash in the government and the Diet that "the Kumamoto District Court judgment must not be recognized." The newspapers started to report that the thinking that was spreading in the government was "appeal, then negotiate."

We were ready to do what it took, including holding assemblies and sit-ins in front of the Prime Minister's residence and the Diet building.

Since we plaintiffs might meet with the Prime Minister and did not want to be impolite, we

decided we would wear coats and ties. It was May and the sun was beating down like mid-summer and there was concern that some among us would suffer heat stroke or even die of the heat.

We all came to the realization that “We’ve been waiting for ninety years. However much we might have to wait now, we’d rather wait than accept a half-baked resolution.”

Finally, the Minister of Justice Moriyama Mayumi came to meet with us in her official office. One by one, we earnestly told her of our experiences. When we were finished, she said, “I see. I will consult with the Prime Minister. Please wait for a while.”

Then Mizoguchi Seiji-san from Kyūshū replied quite formally, “We understand. We will be happy to wait while you are considering the situation. We will wait here in the Office of the Minister of Justice.”

“Wow! Mizoguchi-san, you’re great!” I thought to myself, applauding him in my heart.

Back at the sanatoria, hunger strikes had started. There was continuous news coverage on television and in the newspapers. Citizens and supporters from throughout the country were flooding the Prime Minister and Minister of Health and other officials with faxes and postcards calling for “No Appeal!”

Every member of the Diet with a heart, from all parties, found a room in the Diet Building to serve as struggle headquarters and worked their hardest to ensure that there would not be a half-baked resolution.

As we plaintiffs and representatives of the legal teams began our sit-in in front of the Prime Minister’s Official Residence, we were informed by security that if we continued, we would be “removed.” If we kept up our confrontation, security would use actual force on us. Crossing political party lines, a group of

female lawmakers surrounded and protected us.

This was cause for happiness. At that moment I truly felt that when you are giving all you have to fight for justice and truth, your struggle transcends political positions and spurs people into action, everyone pulling together and charging forward like a scrum in rugby.

Shaking Hands with Prime Minister Koizumi

Having joined together in struggle even to death, we found that the new prime minister, Koizumi Jun’ichirō, was willing to meet with the plaintiffs.

At first a secretary told us that “as the Prime Minister is a busy man, ten minutes are allotted for this meeting,” but I believe it lasted for about an hour.

When one woman among us told him that, “I was made to abort my baby. A life that had already begun was lost. I want my baby back,” he hung his head, truly at a loss for words.

Koizumi listened to our earnest plea “Please do not appeal” and finally grasped hands with each of us.

We all felt that with that handshake Koizumi had dropped the appeal, but the evening newspapers reported that “Government proceeds to appeal.” Our hearts were in turmoil. There were developments minute-by-minute.

Then, a press conference was called in a conference room at the Legal Association and reporters were called back. What was happening? My heart was pounding.

When we entered the neighboring meeting room, we were greeted with cheers. What is this? I asked the person next to me.

“The television screen is saying ‘Prime Minister Drops Appeal.’”

When I heard that, my body went limp and I felt as if I were riding on a satellite, floating through space.



In the photo that appeared “above the fold” in every Japanese daily (here from the *Mainichi*) on the morning of May 24, 2001, Usama shakes hands with Prime Minister Koizumi Junichirō as his fellow plaintiffs Chiba-san and Kunimoto-san look on.

Hot Tears of Joy

We were all weeping. Holding each other and sobbing.

If you turned to either side or looked behind you, there was someone in tears.

I, too, was completely in tears.

For the first time in my seventy-five years, I was drenched in tears of joy.

Tears of happiness are warm, even hot.

Those were my genuine feelings. Nothing fake.

Tokuda Yasuyuki-san, the head of the plaintiffs group, sat on a sofa with his coat over his head, sobbing. Even though reporters were waiting to interview him, he couldn’t tear himself away from that sofa.

Once we had contained our emotions, another set of honest feelings crossed our minds: why, when it was the government and the Diet which did these terrible, unconstitutional things, were we, who had lived this destiny of unspeakable suffering, the ones who had to bow our heads and plead with them?

The news that “Government Drops Appeal” was reported in the newspapers on May 24.

Those newspapers ran the photo of me shaking hands with Prime Minister Koizumi.

My Feelings Renewed, Another Challenge Awaits

It was about three years after our victory in the lawsuit. The Inland Sea was glistening in the spring sunshine and the cherry blossoms were nearing full flower when an acquaintance visited me from Nagoya on a calm, sunny day.

“Usami-san,” he told me, “there’s this mother in her thirties who said to me, ‘I had no idea there were such pitiful people in Japan. Mr. Koizumi was so courageous to come to their aid.’ ‘That may be so,’ I replied, ‘but the ones who showed true courage were the former Hansen’s Disease patients themselves, and their attorneys and supporters. It was because they put everything on the line that Koizumi stopped the appeal,’ I explained to her. Then her face grew anxious. ‘I wonder if my children will get Hansen’s Disease,’ she asked. I wanted to keep talking with her but...”

"I can't really blame her," I replied.

"I wanted to talk to her in easy-to-understand terms, and I'm frustrated at not being able to do a good job."

"I wish the national and local governments would make more of an effort..."

"Then everyone involved has to make a positive effort to accomplish that."

"And we have to argue for living human rights, not charity or comfort."

That was our discussion as we sipped our tea.

I realized that I would have to take on another challenge. Though we had won the lawsuit, there was still work to be done in society so that people would not be prejudiced or discriminate against each other.

When I became a plaintiff, I had to tell the story of "my own life and experiences" in court and I revealed what was in my heart. And we won.

When the judgment was affirmed, Ms. Seko Yukiko hugged me and said, "Usami-san, now it's time for you to go home to Aichi, don't you agree?"

"My brothers are still there, so I can't go home," was the only answer I was capable of giving.

Her kind words were meant to encourage.

I wanted to return to my hometown, but I could not. That was the reality of society.

These feelings were like a knife in my chest.

Many Usami Osamus in my Heart

I am a Hansen's Disease sufferer. Just with that I have experienced suffering and humiliation that cannot be described. I have had to endure the outrages of society and government. It is certain that there have also been benefits from these experiences. That is what I learned from the court struggle.

"If you are going to build a society without discrimination or prejudice, you can't run away from difficult realities," one self inside me scolds another. There are a number of selves inside me.

Unless the seeds in the heart are smashed, we cannot eliminate from this world the heart that nurtures the discrimination and prejudice that must be recognized as human nature. To change government and society, I must first change myself, I came to understand listening to myself.

Here, I suppose, is the final barrier I must overcome.

I'll never be able to forget what West German President Richard von Weizsäcker said twenty-two years ago in 1985, on the occasion of the fortieth anniversary of the end of World War II: "They who close their eyes to the past will ultimately be blind to the present. They who do not carve the memory of inhuman actions on their hearts will easily be swept up in future dangers." Repenting for his own country's acts of aggression and looking at history directly, he made quite an impression with the words of his address to the world, entitled "Forty Years in the Wilderness."

What I can do, I thought to myself, is testify to the facts of history as someone who has actually experienced Hansen's Disease and tell my story as a living witness in order to build a society where this will not happen again.

Here, I thought, is the way to use what abilities I have to regain my own humanity. Surely there can be no restoration of our humanity without

building bonds, person-to-person.



Usami travelled widely, thanks to devoted friends. Here he is in India in 2008, speaking at the 17th International Leprosy Congress held in Hyderabad, along with members of IDEA-Japan.

I Have Been Able to Live Because of My Friends and Comrades

I have lived in a leprosarium for over half a century and so clearly it has become my second hometown. Do I have the luxury to think that it will be my final home? Or would that be a mistake? Probably best to avoid such a thought.¹⁰

Even though I have only bitter and sad memories of my hometown, my old hometown, the longing to go home, just once, comes and goes in my heart.

At the same time as I have a strong desire to pay respects at my parents' grave and then holding a chrysanthemum bid this world farewell, I am old now and blind and cannot walk without a cane, and so I wish just as strongly to breathe my last breath quietly, here at Nagashima Aiseien, my second hometown, surrounded by those with whom I have shared

so much joy and sadness. Those are my honest feelings.

These feelings are the modest yearnings shared by the former Hansen's Disease patients living in leprosaria for their final days. These are their real feelings, not hidden by any lies.

But what makes me truly happy is to be able to talk to everyone here.

I have never married and of course I have no children or grandchildren, no descendants. When I think of this, I am so filled with regret.

What I do have are my friends. My comrades-in-arms. There is no limit to the kindness and comfort they offer. Religious charity is important, but it has its limits.

I believe that in order to resurrect our human rights we must build a government and a society that brings the constitution to life. Everyone I see daily here at Nagashima Aiseien and my friends at leprosaria throughout the country who share this hope have given me much encouragement.

I may have no home to go home to and no family, and I have these handicaps, but I rejoice that my heart is knit together with tens or even hundreds of friends. I call them my comrades.

When we won the lawsuit, I regained my courage when I realized that we are no longer thrown away by the Japanese people. I'm glad of that.



Banreizan, the collective mausoleum at Nagashima Aiseien, following its post-lawsuit renovation.

Life is what still lies ahead

Oddly enough, in a certain sense, Hansen's Disease patients are all equal. The family I was born into was known locally to be rather well off. As a result, they were able to buy Promin illegally. Even so, what mattered was my illness and because of it, I was cut off from my parents and brothers. It was so cruel.

When I arrived on this island and was stripped naked and put in the Kresol disinfectant bath, I entered a society where whether or not you had property outside matters not one bit. Likewise my individuality and my dreams for the future mean nothing. The sum total of Usami Osamu was this: (former) Hansen's Disease patient.

In modern society from Meiji to Heisei, we

former Hansen's Disease patients have been made to live under government policy for "the goal of extinction." Our families also faced hardships: suicide, divorce, prejudice

State policy was to have us "live in order to become extinct," but it can be said of each and every one of us, "we lived, we survived."

The "strength that allowed us to survive" showed itself when the government lost the lawsuit on May 23, 2001.

Into the darkest depths of the sea, where the light of the sun has never before reached, there at last sunlight has started to break through. Out of this aspiration to live a life never deviating from the path of peace and social progress so that the warmth of the light of welfare and of the truth of the Constitution might reach the weak and mistreated, I became a member of the Japan Communist Party and now I intend to value the remaining life that has been granted me and to continue my work as a *kataribe*, a living witness. Life is what lies ahead...

I continue to believe that the truth has the power to change human history and lead to social progress.

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scars of Korean forced labor

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Notes

¹ Usami uses several terms here—*kanja* and *moto kanja* (patients/former patients), *nyūshosha* (“residents”/admittees), and *byōyū* (friends in illness)—while rejecting the word *raisha* as dehumanizing as its English equivalent *leper*. Likewise, since the 1950s, the term *Hansen-byō* (Hansen’s Disease) has replaced *raibyō* in general and scientific discourse, with the latter considered far more stigmatizing than the English leprosy, which remains common in many parts of the world. Usami also uses the term *shūyōjo* (incarceration/ concentration facility) which is often used to translate both Nazi concentration camps, a comparison Usami himself made in the pages of *Time* magazine in 1996 following the repeal of the Leprosy Prevention Law, and Pacific War-era U.S. and Canadian “relocation centers”/internment camps for their citizens and residents of Japanese ancestry.

² See [here](#) and [here](#).

³ A month after Usami’s death, the two leprosaria located on Nagashima Island—Aiseien which was opened in 1931 as the flagship of a new system of national institutions replacing local and missionary hospitals and Oku Kōmyōen which was relocated from Osaka Bay following the Muroto Typhoon of 1934—celebrated the 30th anniversary of the “Bridge of Restored Humanity” which connects the island across a narrow strait to Honshū. At that time it was reported that the combined population of the institutions was down to 261—nearly 7,000 having died there—with an average age of well over 85. A move is underway to register the two institutions, as well as Ōshima Seishōen on another Inland Sea island, as UNESCO World Heritage Sites. Perhaps Usami would have agreed. See [here](#).

⁴ The first effective treatment for Hansen’s Disease, the sulfone antibiotic Promin was developed at the United States Public Health Service Hospital in Carville, Louisiana, in the early 1940s and was introduced into Japan during the Occupation.

⁵ Ogawa Masako was a doctor at Aiseien in the late 1930s. Her 1938 memoir *Kojima no Haru* was made into a popular film in 1940.

⁶ Following the lawsuit, a professionally-curated [museum](#) was established in the former administration building and many of the artifacts Usami collected are now displayed there.

⁷ Although the *jūkanbyō* at Aiseien is only a ruin with a historical marker, the one at Kiryu Rakusen-en at Kusatsu, where numerous patients froze to death, has been reconstructed as a [museum](#). That work was led by Usami’s comrade Kodama Yūji (1932-2014)

⁸ Prior to the development of antibiotics, oil extracted from the fruit of the tropical Chaulmoogra tree was the only medical treatment available. There is some debate as to

whether it was at all effective.

⁹ As Usami indicates here, Shima Hiroshi (1918-2003) was among the leading and most forward thinking Hansen's Disease patient-activists. A novelist and editor as well as political activist, he spoke out about the parallels between the Hansen's Disease experience and how Japanese infected with HIV were being treated in the 1990s and called for the repeal of the hated law. After making a life at one leprosarium in Kagoshima Prefecture, Hoshizuka Keiaien, for fifty years, he exercised his hard-fought right to "return to society" for the last several years of his life.

¹⁰ Usami is referring to a major cause of unease among the remaining residents of Aiseien and the other national sanatoria: the question of whether, as their numbers decrease and their need for care compounds, the Ministry of Health, Labor, and Welfare may decide to break its oral promise and forcibly relocate them once again as a consolidating and cost-saving measure.