# A Medical Organization That Has Broken Down the Barriers to Minamata Disease (Methylmercury Toxicosis) Treatment and Research in Japan by the Government and the Medical Community for Half a Century

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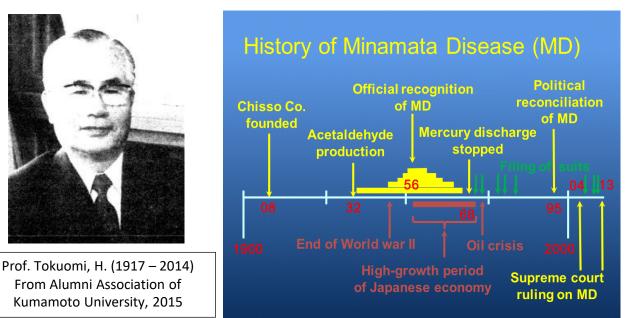
#### **About Minamata Disease**

Between 1932 and 1968, methylmercury-contaminated wastewater was released from the Chisso Corporation, and an estimated 500,000 people in the Minamata area were subsequently exposed to methylmercury. The disease, which came to public attention in 1956, was soon named Minamata disease, and was finally formally recognized by the Japanese government in 1968. Researchers at Kumamoto University studied severely affected residents in search of the cause. The intensity of research gradually decreased due to political and economic power, but regained momentum when Kumamoto University conducted a large epidemiological study (1971-1973). However, the results were ignored and further research on Minamata disease was reduced. There has been no constructive research on pollution by the government at any level.

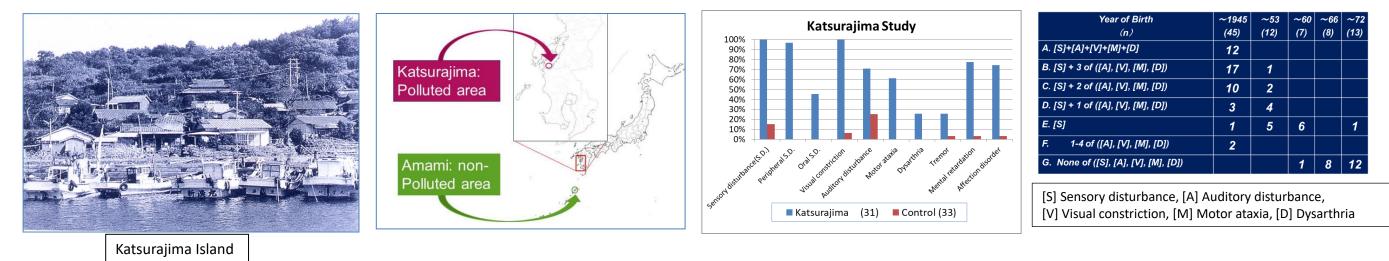
#### From the outbreak of the disease (1956) to the end of acetaldehyde production (1968)

In 1956 (April), two sisters, aged 2 & 5, were admitted to Chisso Hospital. From 1956 to 1960, H. Tokuomi et.al in 1st Internal Medicine Department, Kumamoto University reported 34 cases of Minamata disease. In July 1959, the Kumamoto University Study Group determined the cause to be a type of organic mercury. The next day, the government disbanded the group.

Chisso continued production thereafter. Mercury-contaminated wastewater continued to be released until 1968. Dr. Tokuomi et al. studied 34 cases of severe Hunter-Russell syndrome. From this and subsequent studies, he concluded that Minamata disease had ended by 1960, with a total of only 87 patients. There were no further clinical studies for more than 10 years. In 1961, Dr. Tatetsu became a professor in the Department of Neuropsychiatry at Kumamoto University. Prof. Tatetsu started research and at the same time Dr. Harada found fetal Minamata disease in 1962. They thought that milder cases were overlooked in the diagnosis of Minamata disease.



In 1971, Kagoshima University and the Kagoshima prefectural government surveyed Katsurajima Island and found very few Minamata disease patients there. But after the survey, many of Katsurajima's residents were officially certified as Minamata disease patients.



This study supported the introduction of the criteria that a patient who had been exposed to methylmercury and had sensory disturbance in four limbs should be diagnosed with Minamata disease. Our criteria were supported in the "Second Minamata Disease Lawsuit" filed at the Fukuoka High Court in 1985. However, the government did not accept this decision. The Environment Agency again appointed Prof. Tsubaki as chairman of another "expert panel" and the panel accepted the "1977 criteria". However, when the Japanese Society of Psychiatry and Neurology\* asked the panel for details, they did not receive clear information about any scientific data.

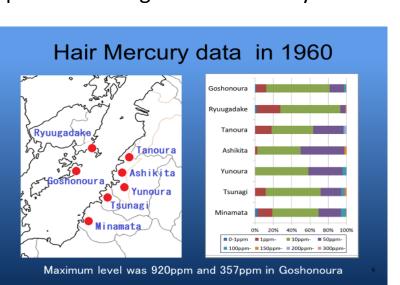
\*The "Japanese Society of Psychiatry and Neurology" is a society mainly for psychiatry and different from the "Japanese Society of Neurology," which Prof. Tsubaki et al. founded and belonged to.



Children of Congenital Minamata Disease, 1962

From 1960 to 1962, hair mercury levels were studied in some areas along the Yatsushiro Sea coast. In 1960, the hair mercury level was 50µg/g or more in 23.5% (227/967) of the subjects and 10µg/g or more in 85.5% (827/967) of them. Most of these subjects had not been tested at that time. After 1963, government agencies stopped measuring human mercury levels.

In May 1968, Chisso finally ceased production of acetaldehyde. In September, the Japanese government officially recognized that the cause of Minamata disease was methylmercury in the wastewater from the Chisso factory. In March, Dr. Fujino (one of the authors) graduated from Kumamoto University and took a position in the neuropsychiatry department the following year.





Prof. Harada, M. Prof. Tatetsu, S. (1934-2012) (1915-1999)

### From the outbreak of the disease in Niigata (1965) to "Mercury Panic" (1973)

In 1965, a second Minamata disease broke out in Niigata, where the Syoden Kanose factory produced acetaldehyde and discharged mercury-contaminated wastewater into the Agano River. Prof. Tsubaki of Niigata University, one of the founders of the Japanese Society of Neurology (1960), discovered Niigata Minamata disease. He began medical examinations and measured concentration of mercury in the hair of all residents of the polluted area. He found milder cases in the exposed residents and diagnosed Minamata disease with sensory disturbances only (without ataxia, visual constriction, etc.).



In 1969, the patients demanded compensation from Chisso and filed a lawsuit. The Minamata disease patients did not receive proper compensation until the case was settled in 1973. In 1970, Fujino studied junior high school students and found milder neurological and psychiatric abnormalities in those born in the 1950s, the same period in which fetal Minamata disease patients had been found.

After 1970, a group of volunteer doctors began going door to door and examining residents in the Minamata

Prof. Tsubaki, T.

In 1978, the Minamata Clinic was rebuilt as the Minamata Kyoritsu Hospital to provide inpatient care for patients. Dr. Fujino and his colleagues continued to provide medical examinations in the contaminated areas and expanded their activities to Yatsushiro City (north), Akune City (south) and Azuma Town (west). By the 1990s, a total of 10,000 residents had received medical examinations. In 1987, a health survey was conducted in the Yatsushiro Sea area. 1,088 residents were examined, and more than eighty percent of the subjects were found to have sensory disturbances in four limbs and other neurological abnormalities.

In 1995, as part of the settlement of the "Third Minamata Disease Lawsuit," the government agreed to compensate Minamata disease patients based on the criteria of four-limb sensory disturbance of the hands and feet. More than eleven thousand victims were compensated by this settlement, and the criteria became the norm for the future compensation of a large number of victims.



Foundation of Minamata Kyoritsu Hospital (1978)

# From Supreme Court Judgment (2004) to Time-Limited Relief (2009-2012)

Even after the 1996 settlement, the Kansai Minamata Disease Lawsuit continued. On October 15, 2004, the Supreme Court ruled that the government was responsible for the spread of Minamata disease and certified milder cases of the disease. Following the ruling, the governor of Kumamoto Prefecture, Yoshiko Shiotani, proposed a health and environmental research plan for the polluted area. But the Environment Agency refused and did not change its criteria and policy.

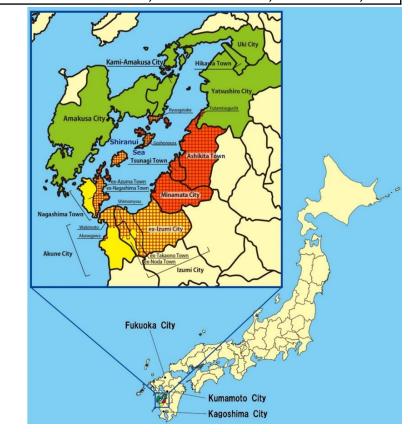
However, the number of patients asking to be screened for Minamata disease began to increase. We have screened several thousand residents. Until 2004, residents had been reluctant to complain about pollution and health problems because of the pressure of discrimination. The court ruling relieved that pressure. In 2009 and 2012, we conducted the Yatsushiro Sea Coastal Area Health Investigation and found that 87-90% of the subjects had signs and symptoms of Minamata disease.

Following the filing of the No-More-Minamata Disease Lawsuit (2005), the government enacted a temporary special law\* in 2009 to provide relief, and 55,658 victims were compensated. However, the government revoked the policy of the law in July 2012, leaving many patients in the area without the compensation to which they were entitled. This also meant that the criteria were again limited to a specific area and a specific age group.

Number of Minamata disease patients	Kumamoto	Kagoshima	Total
Patients Certified with Minamata disease (until April 2022)	1,791	493	2,284
Patients with Definite Sensory Disturbance, who received Partial Compensation (December 1995 to July 1996)	8,834	2,706	11,540
Settlement in the No More Minamata Disease Lawsuit	(Data by prefecture not disclosed)		2,794
Patients Compensated with Medical Expenses			
(about 10,000 uncompensated patients were excluded)	37,613	15,543	53,156
(from 2004 until and including July,2012)			
Total	48,238	18,742	69,774

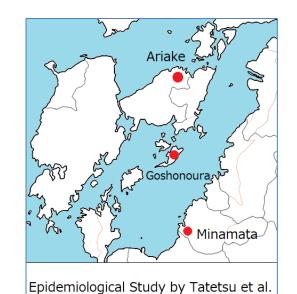
#### The spread of health problems as seen in the 2009 health survey

Since 2009, when the special measure began, many residents with Minamata disease have been found in the outlying areas along the Yatsushiro Sea coast. We found that the symptoms and signs in these areas were the same as those in the central areas near Minamata City. In 2016, we calculated that more than 10,000 people had been examined. Overall, the health effects of the subjects who had lived in the polluted areas around the Yatsushiro Sea are the same, and the spread of methylmercury poisoning is greater than we previously thought. Even younger people are showing symptoms of methylmercury exposure. The results of long-term population studies show that a large number of residents continue to develop health problems. However, with the exception of the Katsurajima Island study, much of our research has been limited to subjects who hoped to be screened for Minamata disease. Recently, we have collected population-based epidemiological data. The attributable fraction was calculated by Prof. Tsuda of Okayama University and was already over 95% in the designated area. In 2015-17, we compared the prevalence of sensory disturbance between the three undesignated exposed areas (Miyanokawachi, Himedo, and Nagashima) and Amami (control). The prevalence of sensory disturbance (both touch and pain) in the subjects' four limbs was 37.8-58.6% in the three undesignated exposed areas and 1.4% for Amami. The attributable risks of sensory disturbance for the three undesignated exposed areas were 96.2-97.6%. This indicates the spread of Minamata disease outside the designated area.



area. Under these circumstances, Fujino began to examine residents and patients in and around Minamata City. When Fujino visited patients' homes, he found patients suffering from severe symptoms of classic Minamata disease who had been left at home without any medical diagnosis or treatment. In 1972, Fujino stayed at a hospital in Minamata and began medical examinations of patients who had been left without diagnosis or treatment. It was then that he began to study the disease in depth.

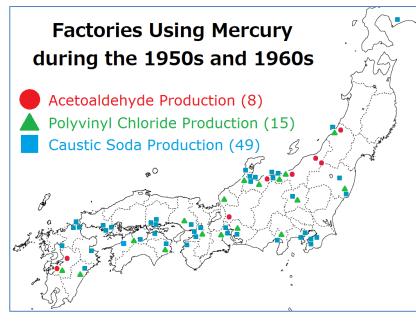
(1921-1987) From Compiled Works from Niigata University & Tokyo Metropolitan Neurology Hospital, 1990

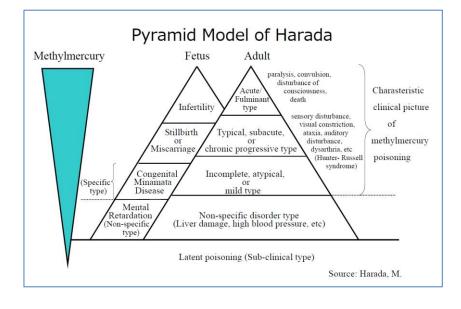


From 1971 to 1972, Prof. Tatetsu conducted an epidemiological study in Minamata, Goshonoura and Ariake (control). He found that in one district of Minamata, 28.5% of the population suffered from Minamata disease. In Goshonoura, cats had gone "mad" and died. In 1960, one of them was found with a record high level of mercury in its hair (920µg/g). In March 1973, Tatetsu reported that he had found more victims than expected. He noted the existence of a chronic, milder form of Minamata disease caused by lower levels of methylmercury, and that some of the victims had begun to show symptoms of the disease after 1968.

He also found residents with symptoms of Minamata disease in Ariake, the control area. There were two other factories that used mercury in the control area. After this report was announced by the media, a "mercury panic" broke out in Japan.

At that time, there were more than 70 factories in Japan that used or had used mercury. The Mercury Research Group of Yamaguchi University suspected three patients of Minamata disease in Tokuyama, where two large factories used mercury. The government appointed Prof. Tsubaki as the chairman of an "expert panel," and the "experts," including Tsubaki and Tokuomi, refused to acknowledge the existence of any other Minamata disease in Japan other than the one discovered in Minamata without further clinical and epidemiological research. Following this unsubstantiated conclusion, epidemiological studies were blocked, and certification criteria became stricter than before. In 1977, the government decreed that sensory disturbances and other symptoms, such as ataxia and visual constriction, must be present in order to be diagnosed with Minamata disease.





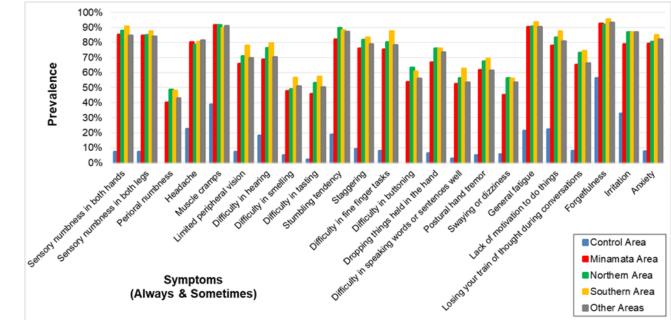
These criteria became known as the "1977 Criteria. Meanwhile, the government strongly advised Japanese caustic soda manufacturers to find and implement alternative processes that did not use mercury.

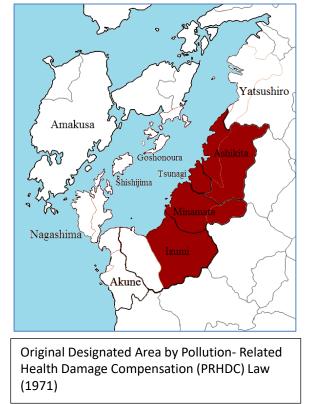
After observing many residents, Dr. Harada proposed a pyramid model of methylmercury poisoning. However, after the "mercury panic," further study of mercury poisoning by the Kumamoto University group became so difficult that it was almost impossible.

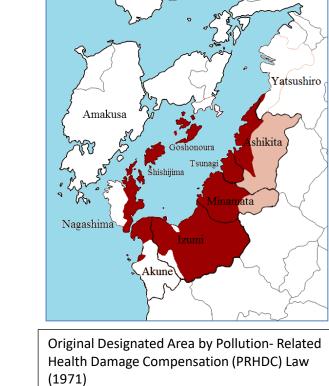
# Foundation of Minamata Clinic (1974) to Political Resolution (1996)

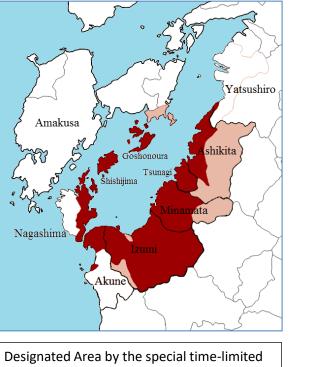
In 1974, Fujino established a clinic across the street from Chisso Company, and later founded Minamata Kyoritsu Hospital in 1978. They began caring for local residents and patients with Minamata disease. At that time, thousands of patients were left untreated in the contaminated area. Their main symptoms were somatosensory disturbance, upper/lower limb and truncal ataxia, visual constriction, auditory disturbance, and so on.













special Law\* (2019-2012)

Area where patients with Minamata disease symptoms have been observed by now

In Japan, a physician cannot diagnose Minamata disease freely. If a resident wants to be diagnosed and treated for Minamata disease, they have to be certified by the government, even if they had the same history and same symptoms of methylmercury poisoning. It is not only the history and physical examination that has to be taken into account, but also the residential area must be within the government designated areas. The left figure was designated area decided by the Pollution-Related Health Damage Compensation (PRHDC) Law (1971). But soon Minamata disease spread outside of that area (second left figure). After 2009, during the period of the time-limited special law\*, the areas spread a little further (second right figure). However, many patients have been found in more outlying area (yellow areas in the right figure)

\*The Law Concerning Special Measures for the Relief of Minamata Disease Victims and the Settlement of Minamata Disease Issues

# The Current State of the Minamata Disease Issue and the Future



#### The clinic began making home visits to care for Minamata disease patients.

They also visited polluted areas around the Yatsushiro Sea and examined residents and patients. In 1974, Fujino et al. conducted an epidemiological study on Katsurajima Island and found that there were many cases of mild to severe Minamata disease. They found cases of methylmercury poisoning in patients who had only sensory disturbances.

The impact of methylmercury contamination on the residents of the Shiranui Sea coast has been enormous, but the full picture has not been revealed until now. The main reason for this is that administrative organizations, universities and research institutions have not conducted sufficient clinical epidemiological surveys of these areas (inaction). The disease (Minamata disease) must be explained by the symptoms of the residents and patients exposed to methylmercury and other data, and such data were obtained from the above-mentioned surveys and became one of the bases for the creation of the "Common Medical Certificate", which is the diagnostic criteria for Minamata disease.

The "1977 Diagnostic Criteria" were decided by the Japanese government without any basis in medical evidence, as revealed by a survey conducted by the Japanese Society of Psychiatry and Neurology. Although Minamata disease was ignored by the major medical associations other than the Japanese Society of Psychiatry and Neurology, a group of doctors, including doctors from our hospital, conducted research and studies including the above, and based on the data, they created the criteria for diagnosis of Minamata disease (the Common Medical Certificate).

The second Kansai trial in September 2023 recognized the Common Medical Certificate, but the Kumamoto trial in March 2024 and the Niigata trial in April 2024 did not. However, many of the doctors who testified for the defendant government in these trials had never examined Minamata disease patients, including specialists who had served as directors of the Japanese Society of Neurology, which is different from the Japanese Society of Psychiatry and Neurology, and who were unfamiliar with the criteria for diagnosing Minamata disease. In the future, research and patient relief will be required through medical disputes and lawsuits.

Even for a disease that has been ignored by the authorities of major medical associations, it has been demonstrated that by carefully observing, studying and reporting on patients, it is possible to make clinical, research and social contributions that go beyond research institutions.