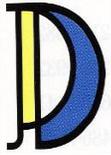


Excerpts from



**Japan Society for Dying with Dignity Newsletter
No. 178, July 1, 2020**

Main Contents:

- New Beginning as a Public Interest Corporation
- FY 2020 Business Plan and Budget Plan Finalized
- Telephonic and Email Medical Consultations (No. 4)

**JSDD finally accredited as a Public Interest Corporation
End of life self-determination regarded as the right to pursue happiness**

Japan Society for Dying with Dignity, Public Interest Corporation

By President Dr. Soichiro Iwao

I am pleased to announce that we have been accredited as a public interest corporation by the Cabinet Office, Committee on Public Interest Accreditation.

In 2012 when I was elected as the president of JSDD, I knew that our main goals would be to legalize the living will and to change its corporate status to a public interest corporation in order to promote the living will nationwide.

Our efforts toward the legalization of the living will began in 2004 including the establishment of the Diet Member Coalition for Dying with Dignity; however, we have not reached our goal yet unfortunately. Considering the difficulty of pursuing the legalization, the government has shifted its approach by promoting “Jinsei Kaigi” (Advance Care Planning), now known as “Life Planning Conference.” Jinsei Kaigi supports a movement of emphasizing consented self-determination obtained through communication among the patient, family members, medical providers, and care givers regarding the patient’s terminal medical care.

Convincing decision from the Committee on Public Interest Accreditation

When JSDD’s corporate status changed to a Public Interest Corporation in 2015, we applied twice to obtain an accreditation. It was rejected by the Prime Minister of Japan on the grounds that permitting JSDD to become a public interest corporation may inadvertently send a negative message (legal disadvantage) by misleading doctors in their decisions regarding terminal

medical treatments. Since we were not satisfied with the decision, we fought the case for three years. We won twice in the first trial and the second trial, and when the government decided not to appeal, we finally won this case on November 11, 2019.

There were some matters pointed out by the court which we discussed with the committee on public interest accreditation for corrections to convince the committee to approve the accreditation.

Starting under our new corporate status, we can now further promote the living will by portraying self-determination as the right of pursuing happiness, guaranteed by our constitution. (4/1/2020)

JSDD's ten year journey finally achieves its corporate status as a Public Interest Corporation

After two applications for public interest accreditation and two appeals to the courts

By Rio Tomono (JSDD Board Director / Doi Attorney Office)

The details of obtaining the status of Public Interest Corporation

It took ten, long years from the start of applying for the accreditation to finally obtaining the approval. Below is a summary of this process.

Two applications for Public Interest Accreditation

First application for accreditation

On April 1, 2010, JSDD started the application process to gain corporate status as a Public Interest Corporation. JSDD was a general incorporated association at that time, and we felt that a corporate status was best for the promotion of the living will. We defined in our application that JSDD's two objectives: 1) to publicize and promote nationwide the concept of dying with dignity, and 2) to maintain custody of the living will while pursuing its legalization.

However, it was rejected on June 5, 2014 for the following reasons:

- Deliberation will be conducted under the current legal system.
- Under the current circumstance of the living will not being legalized, the fact that JSDD manages and maintains the national registry of the living wills generates legal disadvantage to physicians.
- Giving accreditation to a project that promotes the legalization of the living will displays a one sided judgement prior to being decided in legislature who has not reached the decision on the legalization of the living will. I would be giving this project an unfair, prior approval and thus, inappropriate.

There came out a lot of opposite opinions from specialists of the various professions.

Second application for accreditation

On April 4, 2015, JSDD under the status of a general incorporated foundation reapplied for its accreditation. On December 22, 2015, we made a few technical changes in the application which was to make one objective with three sub-goals instead of two: 1) to publicize and promote the living will; 2) to maintain the national registry and custody of the living will; and 3) to conduct research and provide proposal to modify the current living will format.

However, it was rejected again on December 9, 2016. The reason for the rejection was provided as follows:

- Accreditation to a project with a goal of maintaining the national registry of the living will for public interest leaves room for misguided interpretation by physicians that the government positively recognizes or indirectly approves withholding or terminating life-prolonging measures without considering various factors affecting the decision regarding this matter.
- It may have a negative impact on physicians who provide terminal care for the reason mentioned above.
- Given the situation under which the physicians are placed currently, those who execute their patients' living wills may be sued and be held legally and criminally accountable.

In other words, if a project that maintains the national registry of the living will is recognized as a public interest project, physicians will be placed at a legal disadvantage. Once again, we could not accept this reason.

JSDD takes the case to Tokyo District Court to appeal the Committee's decision

After two rejections, we took the case to Tokyo District Court on June 8, 2017, as we concluded that the Committee's reasons for the rejection had a profound flaw. The living will is obviously important from the viewpoint of respecting individual will, but it is also important from the medical providers, as it is a tool to understand the will of the patient. We could not accept the government's stand on this matter.

The First Trial: Tokyo District Court's decision on January 18, 2019

On January 18, 2019 Tokyo District Court decided to revoke the government's rejection of JSDD's application as a Public Interest Corporation. Finally, our viewpoint was fully recognized and accepted.

In court, the government could not provide any solid grounds for their assertion and merely repeated their reasons. The court conducted a thorough examination by referring to current, relevant laws and the guidelines. As a result, it concluded that JSDD's project would be rightfully recognized and consequently would not be of any disadvantage to the medical providers (more details were provided in Newsletter # 173, Page 23). The mass media found this case exceptionally sensational, as revocation of government's rejection was such a rare case. The government was not satisfied with the case's outcome, and appealed the case to the Tokyo High Court.

Appeal to the Tokyo High Court: Final decision made on October 30, 2019

On October 30, 2019, Tokyo High Court supported Tokyo District Court's decision at the first trial. It ruled that contrary to the government's argument, JSDD's project serves as a public

interest, and does not give physicians any disadvantage. The results of this trial provided a more profound significance in the concept of the living will.

Tokyo High Court recognizes significance in the Living Will

Tokyo High Court recognized that the Living will is a worthy tool to protect medical providers from various legal risks from such decisions as withdrawal of life prolonging measures based on presumptive wish and will of the patient. Furthermore it showed that the living will issued by JSDD has a much higher probability of surviving family's refrain from unnecessary legal attacks against their physicians. Consequently, it results in allowing physicians to protect the patient's right to self-determination in making end of life medical decisions.

JSDD has been in pursuit of a society which respects and honors the patient's will to determine the end of life medical treatments and care. This is the reason we publicize and promote the concept of the living will. We are happy that Tokyo High Court finally recognized this point.

A step further: the social impact of Tokyo High Court's decision

In this trial, the definition of "public interest" became the key factor in the outcome. The government committee used discretion in interpreting the word in a broad sense, and seemed to define "public interest" using its own criteria to reject our request. It is clear that the scope of using discretion is now much narrower in light of recent developments and relevant laws. The court's decision was an epic event which was not only significant to our organization, but also gave the same profound significance to the entire society.

What is affected by being a Public Interest Corporation? (Simple, summarized explanation)

1) The reason JSDD pursued a corporate status of Public Interest Corporation

When JSDD started to investigate its corporate status change to a Public Interest Corporation, publicity of the living will was still in its infancy. In a real medical setting, families and medical providers were facing unsolved problems in regards to making terminal medical care decisions. Under such circumstances, JSDD's activities were brought to a higher level of public interest. In order to further these activities to promote awareness of honoring the individual's will regarding terminal medical care, we needed to reach out to the medical community and let them know about who we are and what we do. To pursue the status of a Public Interest Corporation was the next natural step.

Currently the country is publicizing the concept of Jinsei Kaigi (Advance Care Planning), also known as "Life Planning Conference," which is a meeting among family members and medical care team to share and develop one's terminal care plan that the patient wants to be executed. However, there are still many unresolved issues surrounding terminal medical care. Therefore, it was even more crucial for JSDD to obtain the status of a Public Interest Corporation.

2) The changes

- Our government guarantees the quality of public interest.

To be accredited as a Public Interest Corporation meant that the government recognizes the importance of JSDD's activities as public interest, which (benefits an unspecified number of citizens.) JSDD will be known as an organization that conducts activities that support the public

interest, and people will be more open to get involved in projects resulting in increased awareness and wider publicity of the living will, thereby creating a culture that honors the will of terminal patients.

- Tax benefits for donating to JSDD

Donations are a necessary source of our financial income to conduct activities supporting public interest. As an accreditation Public Interest Corporation, JSDD as well as donors will receive favorable taxation benefits.

3) JSDD will move forward hand in hand with all of our members

We would not have been able to achieve this success without the support of our members who have a good understanding of our projects and have helped along the way. We are facing a society with a large elderly population. Our role in society will be more critical than it has ever been. Our activities and effort will be needed more to meet its expectations.

On April 1, 2020, JSDD launched a new start as a Public Interest Corporation. We want to move forward together with all of you members who will help make our society respect and honor the wish of all individuals at the end of their lives.

FY2020 Business Plan and Budget Plan finalized

Launching a new start as a Public Interest Corporation Membership total decreased, but deficit also greatly decreased

FY2020 Business Plan and Budget Plan for the General Incorporated Foundation, Japan Society for Dying with Dignity, were finalized on March 27 by the board of directors through paper exchanges as opposed to the normal meeting due to COVID-19. On June 8, 2020, FY2019 financial statements were also examined and approved electronically.

President Iwao announced last fall that Tokyo High Court had recognized JSDD projects as public interest, and JSDD launched a new start as a Public Interest Corporation in April. In September, the advisory structure consisting of new board directors and subject matter experts from outside to establish a living will study group. The study group's purpose was to assess and analyze JSDD's projection, incorporate "Jinsei Kaigi" (ACP) to the living will concept, and determine and prioritize which projects required acceleration and deeper cultivation.

Current membership status

There were 106,208 members at the end of FY 2019 (the previous FY had 109,155), and we lost 2,947 members in a year. Last fiscal year we lost around 1,000, and the previous year was around 2,200. It seems that the pattern of slowed decrease in membership total has ended, and we're in a rapid decline. The new enrollment was 5,274 which is around 1,000 less than the previous year. The number of cancellations was 8,221 (due to death or failure to pay for three consecutive years. The previous year's cancellation was 7,248, therefore, we had about 1,000 more members die or cancel this year. As to new enrollment, the age group of 70's were about 39 % of total, which remained unchanged for the last ten years. For comparison, the average age

of new enrollment was around 57 years old between 1976 and 1980, and 72 years old between 2016 and 2019.

FY2019 Business Report

We had three business objectives:

- 1) To expand and educate the population about the concept of the living will
- 2) To conduct national registry and maintain custody of the living wills
- 3) To research and propose new activities

As to objective #1, we focused on conveying the need for the living will and the concept of Jinsei Kaigi (ACP or Life Planning Conference) to help people develop their living wills through a method of communicating and reaching an agreement with loved ones about how you wish to spend the final stage of your life. This is especially important in light of an increasingly older population. Due to COVID-19, we were forced to cancel some annually planned events such as speech forums, seminars and visiting lectures, especially in February and March. The number of physician registered in the LW Supporting Physicians Registry System at the end of the fiscal year was 1,988, an increase of 61 from the previous year, though we did not reach our target of 2,281.

As to objective #2 (registry and custody of the living wills) please refer to the current membership status mentioned above.

As to objective #3, both JSDD headquarters and regional chapters held Japan Living Will Study Workshops, and a total of 1,251 people participated (compared to 1,040 in the previous year).

FY2020 Business Plan

As to objective #1, we will continue to promote the need for everyone to have a living will. The ACP, marketed as “Life Planning Conference,” and “My Wish List” which supplements the living will, will be the core of the government project. We will strive to maximize the use of mass media, local newspapers and local television to advertise speech forums and seminars. Our regional chapters will circulate information through social media such as Facebook. Furthermore, we will donate free educational material to local universities, medical schools, nursing schools and health occupational schools. We will also continue to donate free JSDD publications and DVDs to nursing homes, assisted living facilities and funeral service homes. As to the LW Supporting Physicians Registry System, we will make every effort to hit the total target number of 2,393 by increasing 405 physicians to join, and involve them more in speech forums and seminars. We will endeavor for new publications by continuing the sales promotion of the book, “Living Will Notes” published in 2019 by Bookman, and develop classes on how to use it. Also, we will conduct one-on-one training workshops to educate and certify more visiting lecturers and facilitators.

As to objective #2, we will shoot for the total annual membership goal of 6,600 with monthly average addition of around 550. In addition to the traditional methods, we will further this effort by developing a web-based enrollment system, a web-based magazine and the Membership Custody System. As to objective #3, we will continue to conduct the Japan Living Will Study Workshops and Living Will Research Conferences.

FY2020 Budget Plan

Our membership income is projected as ¥144,650,000, a decrease of ¥3,600,000 from the previous year's budget due to a decline of total membership enrollment. We will budget the total recurring income as ¥151,800,000 (including membership income), and the total recurring expenditure as ¥171,000,000, which will bring the balance to a deficit of ¥19,500,000. This deficit will come from the expansion of the living will promotional and educational activities.

FY2019 Financial Report

We started the FY with a budget deficit of around ¥16,000,000; however, with generous donations and restricted activities due to COVID-19, the total deficit was only ¥130,000.

Telephonic and Email Medical Consultations No. 4

Questions from JSDD Members and Answers by Consulting Nurses and Doctors “My husband’s doctor recommended tracheotomy when he collapsed...”



Q: My husband (85) who is a year older than I am, collapsed from a brain hemorrhage two weeks ago. He had surgery, but he is still unconscious and with an artificial respirator. His doctor recommends tracheotomy, but I want to honor his living will. To be honest, I am torn about this matter. The doctor says can't wait any more than two weeks. I have to reply by tomorrow, but I do not know what to say. Does he really need a tracheotomy?

A: Generally, the intubation tube (artificial respirator) will be on for ten days for longer cases, two weeks maximum. The tube may damage his trachea which is sensitive to even a small movement. This can lead to necrosis of the mucous membrane, which is the reason for the maximum time of two weeks. If the artificial respirator is continuously on, a viable option is to remove it from the mouth and have tracheotomy. It is an inevitable procedure because having a tube through the mouth exposes risks of pneumonia or suffocation from phlegm or other secretion clogging the tube.

Q: I don't want to see him in pain and suffering anymore.

A: You might think that he would be in pain because a small incision must be made to insert the tube; however, he will be breathing easier and feeling more comfortable eventually. It is also much easier to remove phlegm, so his pain and suffering will actually be alleviated.

Q: Is it possible to remove the tube and close the incision after having tracheotomy?

A: Yes, it is possible to remove it at a later time when it is no longer needed. The opening will close naturally or with a minor surgery if necessary.

Q: I want to honor his wishes, but I am still in a state of uncertainty.

A: The LW is for the patient in terminal stage. In your case, it seems that two weeks have already passed after the administration of an artificial respirator. This is a critical time to observe for any changes to the patient's conditions. Earlier decision is absolutely preferred, but I sense that the doctor respects your emotions, so he is waiting for you patiently to make a decision. I highly recommend that you talk to your husband's doctor openly about your emotions and state of uncertainty to help you through this difficult time.