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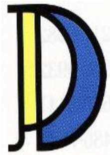

Japan Society for Dying with Dignity Newsletter

No. 174, July 1, 2019

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FY2019 Business Plan and Budget Plan finalized

Amplify informational dissemination of the need for the LW
- More LW supporting physicians needed to support peaceful end of life

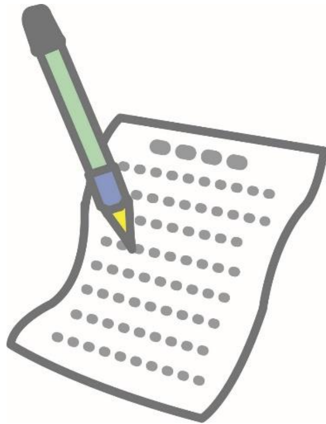
JSDD, a general incorporated foundation, held a board meeting on March 31 and finalized its FY2019 business and budget plans. The FY2018 financial statements will be reviewed by the council meeting on June 29th.

President Soichiro Iwao stated that the government has determined to make a grand step forward to promote the concept of Advanced Care Planning(ACP); therefore, our LW must be urgently and tightly entwined into this government movement. As we live in a society consisting of an enormous percentage of elderly population and an exceptionally high death rate, many eyes are focused on our organization's actions. The president asked all JSDD members to reach out to their respective local communities and tell as many people as possible about JSDD and our mission.

Current membership status

We had 109,155 members at the end of 2018 fiscal year, which is about 1,000 decrease from the previous year, about 2,200 decrease from two years ago, and about 4,000 decrease from three years ago. The numbers indicate that the decline in membership has slowed down. New enrollment was 6,250, about same number as the previous year, and we lost about 7,250 either due to death or failure to pay for three consecutive years. Among the new enrollment, the number of people in their 70's was about 38%, unchanged for the past ten years. Based on our

accumulative data of five year increments, the average age of new enrollment was 57 years old between 1976 and 1980 with a trend of gradual increase in the average enrollment age; now the average age is 72 between 2016 and 2019.



FY 2019 Business Plan

JSDD's objectives are as follows:
#1. To expand and educate the population
#2. To conduct research and propose activities
#3. To be accredited as a public interest corporation

As to objective #1, we will continue to conduct more open forums, visiting lectures and various types of seminars emphasizing the need for LW and "My Wish List" (a LW supplement). We have 39 forums, 136 seminars and 119 visiting lectures, a total of 294 events planned for the upcoming fiscal year, quite a jump from last year's 224 total events conducted.

We plan to conduct educational activities in the academic environment to explain the necessity for the LW in response to requests from universities, medical schools and private middle and high schools. We also plan to participate in prefecture and city sponsored events throughout the country in order to open more opportunities for families to communicate about the topic. Four Chapters including greater metropolitan area have already scheduled such events.

As to the LW Supporting Physicians Registry Program, we will keep reaching out to physicians nationwide so that more will join. We had 1,926 physicians registered at the end of FY2018, and we project an additional 355 physicians with a total of 2,281 physicians to support the program by the end of FY2019. We also plan to reinforce our mutual relationship by conducting meetings with them and posting the list of LW supporting physicians accessible on our website so that our members can search for them in their vicinity.

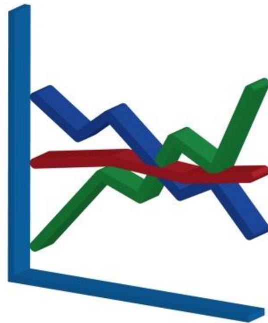
As to publications, we will continue to push the sales of our "Living Will Notes" printed in January 2018 through lectures emphasizing the importance of the LW and how to utilize the notes. We received 282 new enrollment through the Online Registration System we started in February 2018. It is still a small increase, but we expect that more will join online with the help of our online magazine.

Winning the first trial of accreditation as a public interest corporation

As to #2, we will hold our 8th Living Will Study Workshop and its regional meetings. Medical professionals, social workers, patients, general citizens and JSDD staff members will exchange research information and opinions from their perspectives.

As to #3, soon after we won the first trial of accreditation as a public interest corporation, the government appealed against it. Foreseeing a public interest corporation, we must further

improve our organizational details, such as ensuring the head office and the local chapters operate seamlessly as one body, and improving its integrity and internal regulations.



FY 2019 Budget Plan

Our membership income was ¥148,290,000, an increase of ¥3,000,000 from the previous year. Though there was a small decrease in the total number of membership, there was an increase of individual enrollment from removal of married couple discount and a steady increase of life time memberships. Recurring income of ¥154,900,000 and recurring expenditure of ¥169,970,000 brought the balance to a deficit of ¥15,070,000; however, this was almost half of previous year's deficit at ¥28,000,000.

FY 2018 Financial Statements (Draft)

We started the fiscal year with a deficit of ¥28,000,000 but were able to reduce the deficit to around ¥10,000,000 by cutting down on business cost by ¥13,000,000. The major contributors of this success were reduced personnel expenses, increase in sponsorships for regional forums and cost effective efforts for general operations.

Prospect for LW Supporting Physicians Registry System

Report and Interview: Dr. Osamu Yamanaka shares his thoughts on reducing solitary death in the slum of Yokohama

It was a photograph of a person dying in loneliness that changed Dr. Yamanaka forever. "How is this possible? How can anyone die like this in our country?"

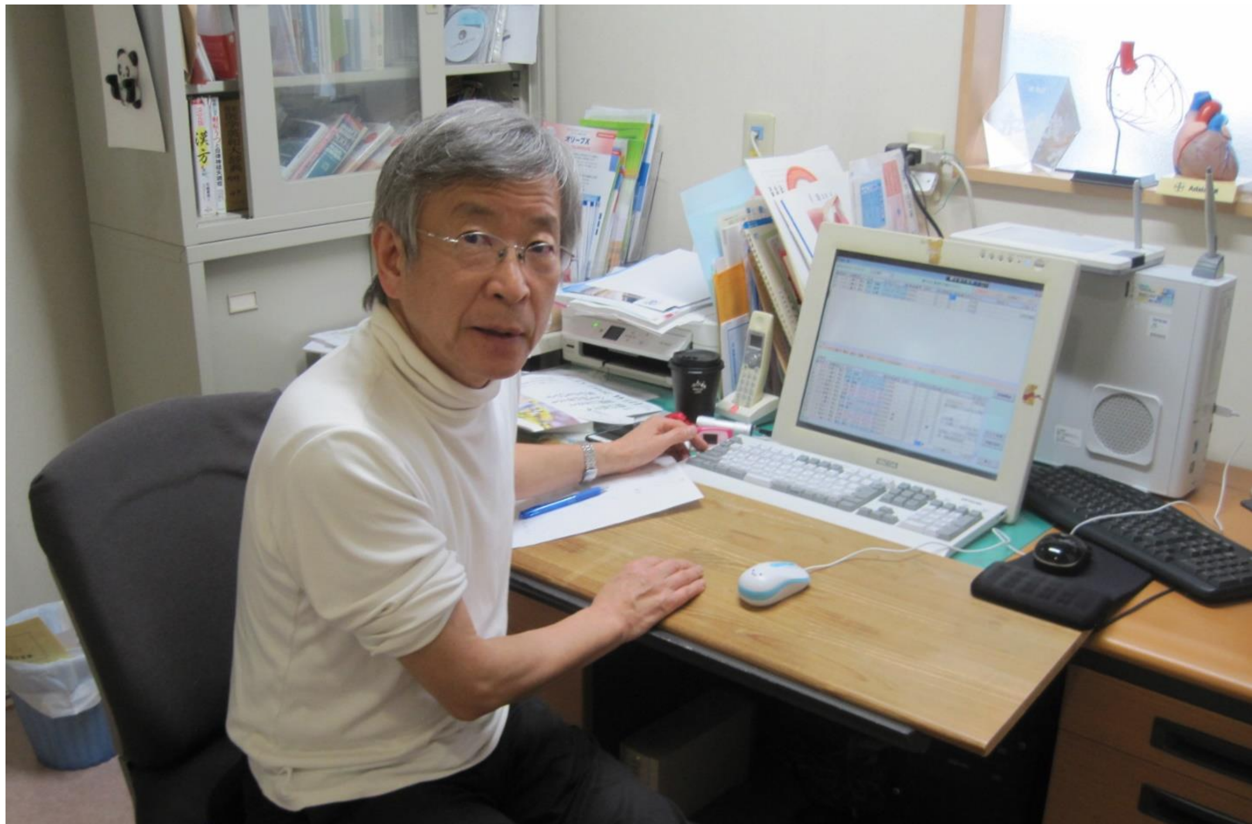
He made up his mind to live in this town and created the "Kotobuki Model." The town of Kotobuki in Yokohama is one of the three major slums in Japan along with Sanya of Tokyo and Nishinari Airin District (Kamagasaki) of Osaka. The word slum is called "doya" in Japanese. A doya is a reversed word of "yado" which means "simple and plain lodge." In the old days, several people would share bunk beds in an open bay, but most lodges today have individual rooms, but very small in the size of 3 tatami mats (roughly 2.7 m x 1.8 m = 4.9 square meters or 8.8 ft x 5.9 ft = 52 square feet) at about ¥ 2,200 (equivalent of approximately $20 USD).

The town of Kotobuki is only about 300 square meters, and packs in 120 such small lodges. Currently, about 6,000 people live there of which 90% are welfare recipients. Many of them are elderly, about half over the age of 65. From the end of World War II until the 1990's, Yokohama was a busy port, filled with import/export cargoes for which many laborers gathered

from all over the country. They were the ones who started to reside in this area which became the town of Kotobuki.

Taking a walk throughout town, there were elderly people wearing ragged jackets and zouri slippers (flip flops) carrying plastic bags from convenience stores and disabled people limping on the street.

It was in 2004 when he was 50 years old that Dr. Osamu Yamanaka (65) opened his clinic near the town of Kotobuki. I was shown a picture of a dead body just prior to decomposition with no one to claim him, and I was told that many people in this town die just like that.



Photograph (Right) – "Solitary death is the dead end of an extended passage for some who have lost their relationship with their society. Even if they die alone with no family, it is not solitary death as long as our team was on their side until their last moment," Dr. Yamanaka says.

Set up of NPO to grade up for Them, Food, Clothing and Dwelling along with Medicine and Occupation

When he was shown the picture, he could not believe his eyes. He saw a lot of medicine bottles piled up next to this dead man. He saw different labels on these medicine bottles. This man was given a lot of medicine, but no one took care of him. He was left alone surrounded by a lot of medicine. "Is this the reality of our medical care system?" I could not accept this reality. I

could not forgive this reality. He recalls thinking that many would consider my reaction to be rather naïve and idealistic. He saw a different world, very different from his own. At that moment, his traditional view and approach to patientcare took a 180 degree turn.
Born in Mie prefecture, he went to Juntendo University School of Medicine. Both of his parents were medical doctors, so his career path was determined by his father. After graduation, he went to work at a hospital in the U.S. and also an International Good Will General Hospital in Yokohama, where he was the department of cardiology chief. His first charity work of bringing blankets to the homeless people in Kotobuki. This was his first encounter with the town of Kotobuki.

In 2000, together with some of his colleagues with similar passion and values, he formed an NPO named “Sanagi-tachi” which provides food, clothing, dwelling, medical care and jobs for the homeless and elderly people living alone. Four years later, he and his colleagues started a clinic to fulfill their goal of fully helping their patients.

After resigning from the good will hospital, he spent eight months before opening the clinic to receive training in dermatology, plastic surgery and urology out of pocket while receiving no income. It is apparent how determined he was to dedicate his life to helping them while living beside them. He often thought of how he should serve his local community while he worked at the Good Will Hospital, but he admitted how difficult it was to overcome his worries and anxieties when he faced the reality of helping Kotobuki.

A model for preventing solitary death

Photograph (Below) – there were mostly wooden old lodges in the past, but we see more new modern buildings nowadays.

When asked, “What triggered you to make this decision?” he paused a while and then said, “The town of Kotobuki is just a small reflection or representation of the whole country, and I knew exactly what I needed to do to stop solitary death.” He added, “I wanted to create a Kotobuki model that could work anywhere, even if I had to dedicate the rest of my life to make it happen.” In 10-20 years, this country’s population will consist of more elderly people and less children. An elderly person will take care of other elderly people and
eventually will be left all alone, dying in solitude. The town of Kotobuki has

the elements of projected future of this country. His idea, which he calls the "Kotobuki Model" is based on a collaborative system in which doctors, nurses, care givers, administrators, local citizens and lodge owners all get together and form a team to take terminal care for those who are without resources or loving families. If the rest of the country can follow and implement the Kotobuki Model, he believes that we can dramatically reduce the rate of solitary death.

The diagnostic statistics of this clinic from January 2005 to February 2018 indicates that the total number of outpatients was approximately 6,700, and the total death toll of identified patients was 402 (excluding 4 suicides). Out of the total death toll, the number of unexpected solitary death in the lodges was 59 or 15% (average age of 66), the number of death in the lodges while receiving terminal care was 133 or 33% (average age of 76), and the number of death after hospitalization was 210 or 52% (average age of 75). Compare to the national average of death while receiving in-home terminal care of 12%, Dr. Yamanaka's team's 33% provided with in-home (lodge) care is much higher.

In 2016, he was presented the 4th Akahige Award by the Japan Medical Association for his dedicated contribution to his local community with his full support to patients in solitude. The Akahige Award originates from a Japanese film directed by Akira Kurosawa and acted by Toshiro Mifune in 1965. Akahige literally translates to "Red Beard." The film is a warm and humanitarian story about a red bearded doctor who helped poor and sick people during the Edo Era (1603 to 1867). The award is given to physicians who possess the spirit of a neighborhood doctor who help the sick and the poor with no family and try to improve their quality of life. What a fitting and deserving reward for Dr. Yamanaka.

Reported by Takeshi Gunji, Editorial Department

Who is a LW Supporting Physician?
They are registered physicians who value the significance of the LW issued by JSDD and declare their support by disclosing their name publicly. The list of registered physicians is available on the JSDD website.

Medical Consultation Phone Calls in FY 2018

"When is the best time to present my JSDD membership card?"

"I was told that I only had three months to live unless I started receiving dialysis as I was diagnosed with diabetic nephropathy. I thought artificial dialysis was an unnecessary life prolonging measure until then, but now I am not so sure about my decision." (90 male)

"Ten years ago, I received a pace maker. This coming fall I'll have to go in to get the battery changed. Once it is changed, it will hold on for another ten years. I do not want to be a burden on my family by living ten more years." (87 male)

"My mother is 89 years old and was diagnosed with middle stage of dementia. I want her to have a natural death, but younger sister's spouse wants her to have the best available medical care. So, we have opposing opinions. Is it possible to let her have a natural death?" (65 female)

Not all calls are related to medical concerns, but various topics such as questions about the Living Will. We have two registered nurses on our professional staff who support our members and their families by providing necessary information and advice.

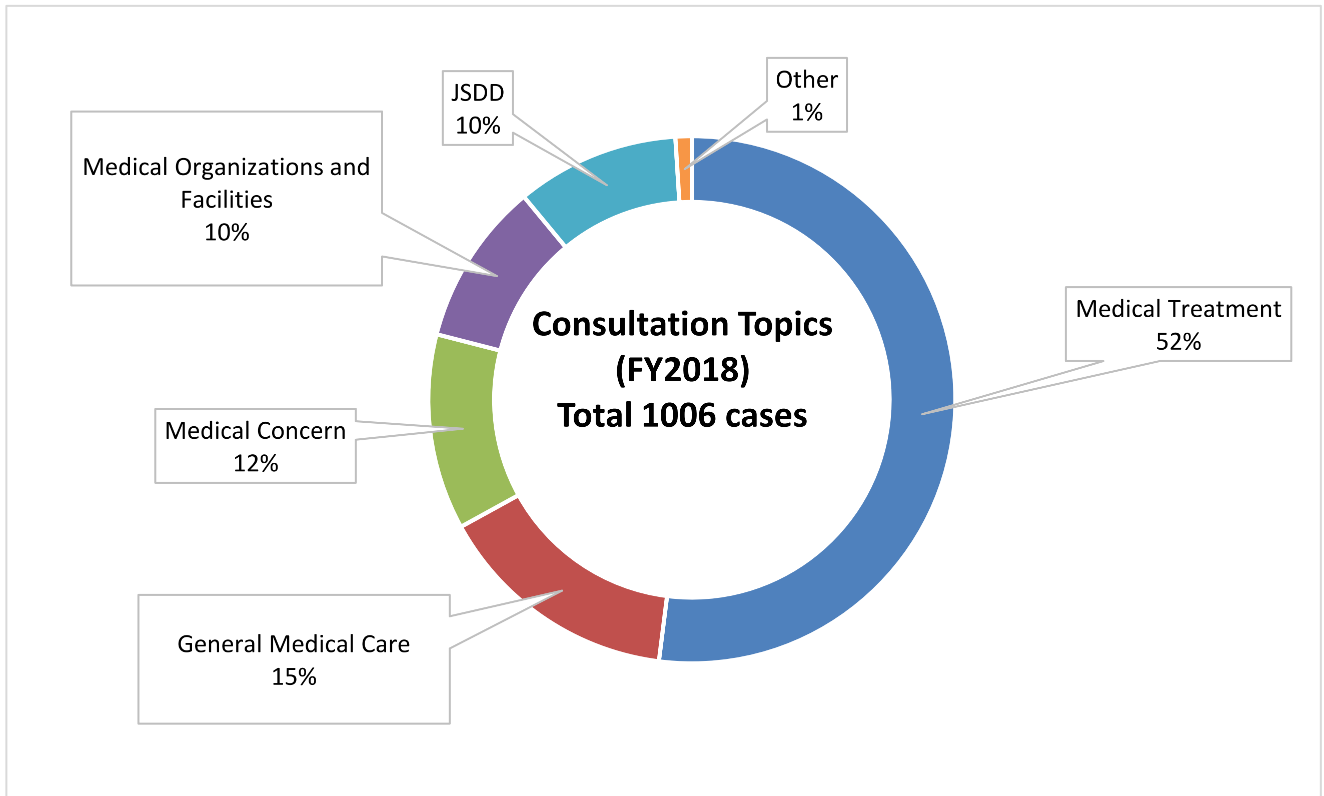
We have now compiled all the results for FY2018. The total number of consultation calls received was 461, which is about the same as the last several years. Itemized call cases (one call covering multiple topics) were 1006, again, about the same as the last four years.

Over half of itemized cases was about "medical treatments" in connection with dying with dignity (523 cases or 52%), followed by general medical care such as conditions, treatments and medications, etc. (151 cases or 15%) and below:
Mental concern (daily worries, anxiety and insecurity) ……………… 120 cases or 12%
Information about JSDD …………………………………………….. 103 cases – 10%
Information about medical organizations and facilities ……………… 95 cases – 10%

Top topic was related to communication

The most common topic of "medical treatment" in connection with dying with dignity breaks down as follows (top 3):
- Improving relationships with medical organization, facilities and family (156 cases)
- Improving communication with primary doctor and family member
- The right time to present the JSDD membership card

The next highest percentage topic was regarding life prolonging measures, such as fear, questions about ventilator, artificial nutrition, fluids and medication. From these contents, we could easily imagine how distressed and confused these patients and their families felt in response to receiving explanations from their doctors about such topics.
We will continue to emphasize the necessity of the living will and provide accurate and useful information about various topics that the members desperately need to help them sort out their issues and confusion during difficult times. We plan to introduce specific questions and discussions we receive by phone and email starting next newsletter without compromising any personal information.



My Wish List

A supplemental document to the Living Will (LW), developed as a response to the increasing ways to spend one's end of life.

"My Wish List" is a compliment to the living will. This document should be in your personal possession and be submitted to anyone or any organization at any time as you see fit.

My Wish List

I have already declared in my living will (Advance Healthcare Directive) issued by Japan Society for Dying with Dignity. In addition, I have hereby documented my specific medical care wishes when my life comes to end. This is my wish list for spending the last days of my life without losing my identity, integrity and dignity.

Date:__________________________ Signature:_____________________________

I checked the boxes of my choosing:

1. Where I wish to spend the last days of my life (mark one box):
   [ ] Home [ ] Hospital [ ] Care facility [ ] Undecided
   [ ] Other (Please specify: ___________________________)

2. What I value the most and want to be honored (mark more than one if necessary):
   [ ] I want to live independently as long as possible.
   [ ] I want to share sufficient time with my loved ones.
   [ ] I do not want to expose my deteriorated appearance to others.
   [ ] I want to eat and discharge myself without any help.
   [ ] I want to spend time in a quiet and peaceful environment.
   [ ] I want to receive all available treatments if there is any chance for recovery.
   [ ] Other (Please specify:__________________________)

The following items, 3 and 4 are to be answered if you have additional comments to the statement, “I refuse life prolonging measures only to extend the dying process”, and/or you need to make more clear about the statement, “I want life prolonging measures to be terminated.”

3. If I am no longer able to eat/drink on my own, and I am diagnosed as terminally ill or incurable, I want to receive the following method(s) of nutrition and hydration (mark more than one if necessary or leave blank if unsure):

   [ ] Nasoenteric feeding through nasogastric tube
   [ ] Intravenous nutrition (feeding through a drip directly into the bloodstream)
   [ ] Enteral nutrition (feeding through a tube into the stomach)
   [ ] Intravenous hydration
   [ ] Fed through the mouth by a care giver

4. If I am diagnosed as terminally ill or incurable, what I don’t want to receive the following treatments (mark more than one if necessary or leave blank if unsure):

   [ ] Cardio pulmonary resuscitation
   [ ] Mechanical ventilator
   [ ] Tracheotomy
   [ ] Dialysis
   [ ] Oxygen inhalation
   [ ] Blood transfusion

[ ] Vasopressor and cardiotonic agents
[ ] Anticancer drugs
[ ] I.V. dripping

5. Other wishes:

(Explanation of medical terms)

- Cardiopulmonary Resuscitation: A medical procedure designed to restore normal breathing after cardiac arrest that includes the clearance of air passages to the lungs, mouth-to-mouth method of artificial respiration, and heart massage by the exertion of pressure on the chest.
- Mechanical Ventilator: A medical device designed to move breathable air and oxygen into and out of the lungs to provide breathing for a patient who is physically unable to breathe sufficiently. It can be administered through a mask, or in more serious cases, a tube is inserted through the mouth or nose. If the condition continues for more than a week or two, a tube is inserted into the trachea by tracheotomy.
- Enteral nutrition (feeding through a tube directly into the stomach): A tube is surgically inserted into the stomach by a percutaneous endoscopic gastrostomy.

Issued by Japan Society for Dying with Dignity