

Excerpts from



Japan Society for Dying with Dignity Newsletter No. 162, July 1, 2016

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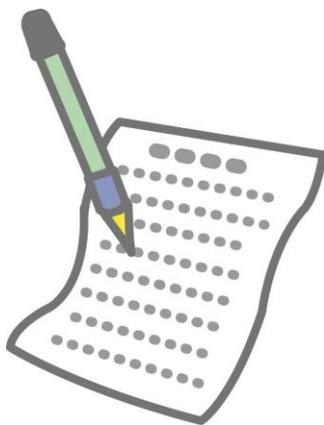
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2016 Fiscal Year Business Plan and Budget Plan finalized

Conduct more lectures for local citizens and strengthen ties with local physicians who support their patients’ living wills

Reformed as a general incorporated foundation, JSDD held a board meeting on March 16, finalizing the 2016 fiscal year business plan and budget plan. 2015 fiscal year financial statements were also reviewed by the council on June 18.

President Iwao stated at the board meeting that as hospitals and local municipal offices are starting to issue their own living wills to patients independently, we must now focus on pursuing our own vision and future perspective.



Status of Current JSDD membership

At the end of 2015 fiscal year, our organization consisted of 116,390 members, about 3,700 decrease from the previous year. We had gained roughly 5,000 new members and lost about 8,800 memberships either due to death or failure to pay for three consecutive years.

FY2016 Business Plan

Our basic policy is to expand, enlighten, research and propose activities pertaining to the living will (LW). To expand LW locally and to enlighten citizens, our major tools consist of lectures, seminars and mini-lecture meetings. We have 220 events scheduled for the

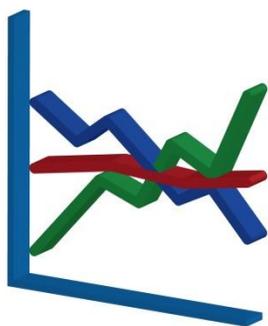
upcoming year so far. Usually, the majority of participants for lecture event are baby-boomers. As such, we plan to develop our younger generation to play a much larger role as lecturers to vitalize these activities. We also plan to reinforce our ties with LW supporting physicians who are registered with JSDD, about 1,350 in total.

We have so far provided a list of LW supporting physicians to JSDD members who request for the information. We are going to take one step further and build a stronger relationship between all of our members at the local level and our LW supporting registered physicians. We will invite them to our LW study forum held by the JSDD local chapters, which will generate a common place to share information and work closely together.

We will also add the list of these registered physicians to our website by region so that the information is easily accessible by anyone at any time. Starting with Chugoku Chapter in July, other chapters will follow suit.

Where we should be in 10 years

As JSDD celebrated its 40th anniversary, the next 10 years will be a decade of turmoil in view of uncertainty in terms of LW legalization and social changes resulting from various LW being issued by other organizations such as hospitals and local municipal offices. We will push the regional chapter directors for deeper involvement in the study and assessment of “what and where JSDD should be in 10 years.” The Ministry of Health and Welfare is now propagating nationwide to establish the service of “Consultation and Support Team” for end of life medical care. As the subject matter expert on LW issuance, JSDD must reach out to those organizations who are just beginning to issue LW and with the national government to work with them closely.



FY2015 Financial Report

Overall deficit was reduced to 2,000,000 Yen against the Deficit Budget of 46,800,000 Yen in the general balance account. Our efforts in cutting down on expenditure, as well as aggressively collecting membership annual dues by sending out notices and reminders had a positive impact on the decrease in our deficit.

FY2016 Budget

Though we may see a decrease in the number of members, we added 6,000,000 Yen to the due income against previous year’s budget, which amounts to 170,250,000 Yen. With the reduction of expenses by moving the Kanto-Koshin-Etsu-chapter office into JSDD headquarters and the reduction of newsletter print cost due to the decrease in the number of members, the total expenditure amounted to 186,770,000 Yen. The balance showed 29,990,000 Yen in deficit; however, this was less than the expected deficit of 30,000,000 Yen included in the budget plan.

Personnel Change

- Mr T. Kobayashi (former Chunichi Newspaper Director) replaced Ms. H. Aoki (retired April 1, 2016) as the new Tokai Chapter president.

- Mr Y, Shindo (former company employee) replaced Mr. T. Kanagawa (retired April 1, 2016) as the new Hokuriku Chapter president.

Over 1,000 medical consultation phone calls in FY2015

over 10% of all cases regarding unsatisfying relationship with their primary physicians



Telephone consultations conducted by JSDD headquarters totaled 1,180 cases in 2015 – first time we recorded over 1,000 cases. After listening to their questions, concerns and anxiety over medical matters, our staff provides them with adequate information and support. This program has shown rapid growth and expansion.

The number of consultation calls recorded are 500, which is 20% more than the previous year. The number of cases by topic or issue, since multiple issues are often covered in one phone call, totaled 965 cases, a large increase from the previous year.

Itemized results show that largest number of cases were regarding “medical treatment” at 457 cases (39%), followed by “dementia,” “living will,” and “other.” There were 134 cases of “unsatisfying relationship with primary care physician” (12%). The topics of “honoring dignified death” (157 cases) and “specific medical treatments” (188 cases) have increased, but the “life prolonging measure” topic decreased to 112 cases.

This decrease may be a result of a sensational documentary released by the media about tube feeding which caused a huge social response. Hospitals and nursing care facilities responded by facilitating consultation between patients, their families and doctors. Although the total number of consultations have increased, the number of calls regarding “forced hydration and nutrition” including tube feeding showed a decrease of 74 cases.

Many calls are emotional due to imminent and desperate state of the callers’ situations.

- Since artificial dialysis is so painful, can it possibly be terminated if we request it?
- Does calling for an ambulance automatically lead to life prolonging treatments?
- I am now at a loss about my treatment policy. My doctor seeks consultation with my family all the time, but I can’t seem to have serious discussions directly with my own doctor.

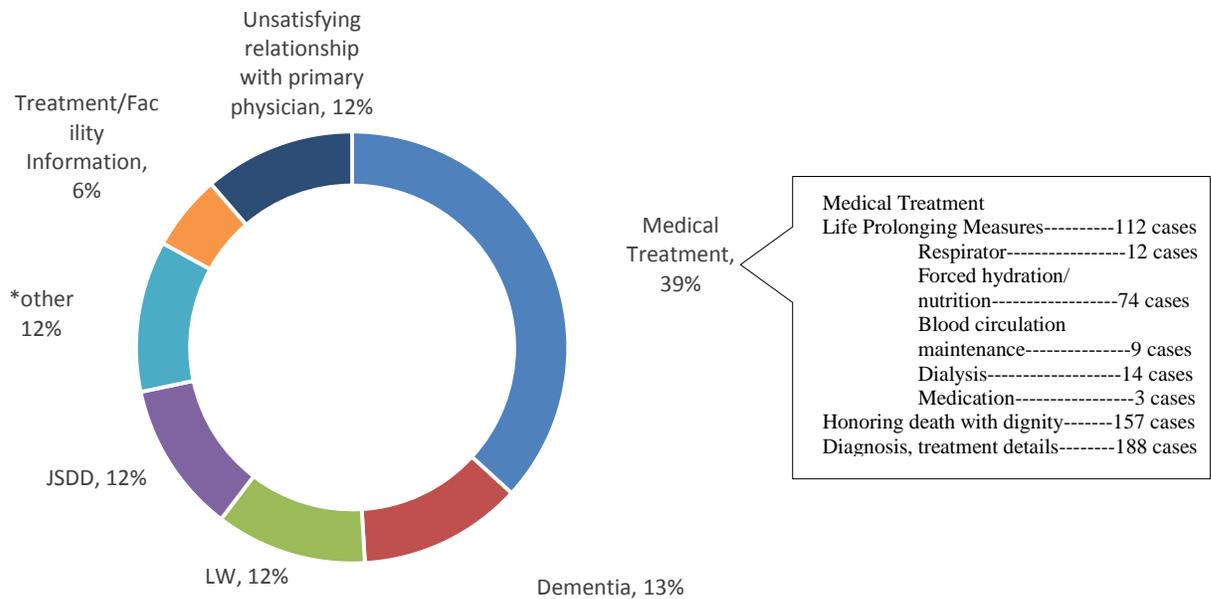
Lately, end of life medical care and LW have become leading topics of our daily conversations. It seems that patients are now expected to seek explanations from their doctors, and medical providers are much more prepared to respond to their patients' questions and concerns. In reality, however, healthcare providers are so busy that patients have less opportunities and are more reluctant to demand their doctors' time, which is the main cause of "unsatisfying relationship with primary doctors" (116 cases).

While listening to the callers' problems, our staff guides them, thereby seeking solutions together. This process helps the callers to sort out their issues, lead to solutions, and prepare themselves to make the next steps. We try to connect them with someone close to the patient or someone from their local hospital or care support centers which are available for continued consultation.

Our staff's advices include making an appointment with the doctor, allowing ample time for these discussions, how to fill gaps between doctors' recommendations versus patients' feelings, and how to ask for explanations of diagnosis. We believe that once the patients start talking and express their wishes to the doctors, their relationship will deepen and be maintained.

We do our best to avoid telling them what to do or making decisions for them. Whether you are a suffering patient or a care giver for your loved one, you're not alone. We are only one telephone call away.

Medical Consultation Contents (2015)



*Other (Fear of living alone, life after retirement, mental illness, etc.)

National LW Issuing Body Liaison Conference

common ground for municipal offices, hospitals, and other medical facilities

LW is no longer issued solely by JSDD, but also by hospitals, local municipal offices and various medical facilities. The new LW era seems to have arrived, but there is no uniform system which allows LWs to be accepted by any medical facilities anywhere nationwide. JSDD stepped up to establish a nationwide LW Issuing Body Liaison Conference (tentative title) in order to make honoring of patient's self-determination a reality.

On May 31, a preparatory meeting was held at the Upper House Diet Member Hall in Tokyo with the following participants:

- JSDD president, Dr S. Iwao and vice president, Dr Y. Suzuki
- A representative from Suzaka City of Nagano prefecture and Miyazaki City of Miyazaki prefecture, both of which now issue LW
- A representative from the Ministry of Health and Welfare “In-home Medical Care Promotion Room”

Documents expressing end of life wishes issued by municipal offices and hospitals



Dr. Iwao made the introduction speech by expressing his gratitude to have been able to see how 40 years of knowledge and experience that JSDD has accumulated are now implemented widely by local governments and hospitals. The importance of the LW is more recognized now than ever, and JSDD would like to take the lead in establishing a national standardized system.

In Japan where standardized national LW system doesn't exist, various styles and forms of LW are currently being issued. These styles can be categorized into four major groups based on the type of the issuing body.

- **Civil Movement Organization:** JSDD, Satisfying Death Society and LMD Research Group
- **Medical Facility:** National Longevity Medical Research Center, St.Luke's International Hospital and Sapporo Teizankei Hospital
- **Public Organization:** Hiroshima Prefecture Medical Welfare Promotion Committee, All Japan Hospital Association, Nagano Prefecture Iida Medical Association and Saga Prefecture Medical Association
- **Local Municipal Offices:** Handa City, Aichi prefecture; Shimada City, Shizuoka prefecture; Komai City, Tokyo; Sapporo City and Moriyama City, Shiga prefecture

The above list is merely a few examples. A publication called “The Ending Note” includes all forms of LW issued in Japan, and are widely sold in book stores nationwide.

The LW issued by JSDD is widely respected both by hospitals and communities in Japan because of its historical achievements and reputation. JSDD's version is far more versatile compared to other formats.

For instance, a LW issued by a particular hospital is for its own patients or a LW issued by a particular municipal office may be only valid in that particular city or town. Some issuing bodies only issue them out, and there is no tracking system or customer service.

Beyond the boundary of various LW styles and formats

How can we make an individually specific LW more versatile? How can we build a social system in which doctors and medical facilities can cooperate without any hesitation? The purpose of the National LW Issuing Body Liaison Conference is to find answers to these questions by providing a common stage for all bodies and facilities that issue the LW.

JSDD has approached all municipal offices and hospital organizations such as all Japan Hospital Association (2,444 hospitals) and another Japan hospital group (2,368 hospitals) to gain their cooperation. We plan to approach the Ministry of Health and Welfare, the Ministry of Internal Affairs and the Ministry of Transportation whose campaigns include quality of life improvement and end of life care to join our efforts towards a common goal.

Project Team formed by Liberal Democratic Party determines to push LW legalization after the Upper House election

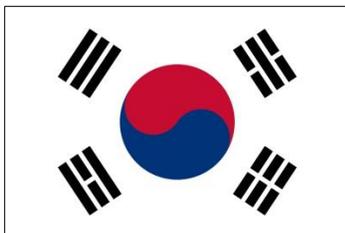
While the bill, “Honoring patients’ self-determination for end of life medical care” has been sitting intact without being submitted to the legislature, Project Team for Dying with Dignity formed by the Liberal Democratic Party had a board meeting on May 31 at its party headquarters. Chairman T. Yamaguchi stated firmly that internal circumstances caused a delay, but they will push it forward immediately after the upper house election.

This bill was drafted by the Diet Coalition Members Federation (196 diet members), and has been stagnant for over two years when it went back to each party for final review and compilation.

JSDD President, Dr. Iwao and VP, Dr. Suzuki attended the board meeting as observers. President Iwao reported that with the recent change in the LW issuance by many municipal governments and other organizations, end of life medical care has become a major social concern. Support for patients’ self-determination is rising rapidly.

Live Report

Hospice Life Prolonging Medical Care Act - Korea legalizes dying with dignity



Patients’ self-determination rights spreading in Asia

Korea’s hospice life prolonging medical care act passed legislature in February, legalizing withdrawal and termination of life prolonging measures. Strictly regulating the conditions for qualification for concerns over disabled and other socially vulnerable individuals made unanimity possible. It will be fully enacted in two years.

“New dignified death law allows termination of meaningless life prolonging measures” (The Kyunghyang Shinmum)

“Death with dignity, patients’ choice, will be enacted in 2018” (Seoul Daily News)

Many Korean newspapers welcomed the new law. One of our reporters visited Seoul, Korea at the end of April when the atmosphere was still hot and alive, and interviewed some key individuals who played major roles behind the screen for their explanations of the new law.

First of all, this law stipulated documentation and registration of the LW (called “advance directive of life prolonging treatment” in Korean). Any person who is 19 or older can express his/her wish for withdrawal or termination of life prolonging measures and for hospice palliative care.

The Ministry of Health and Welfare stipulates this documentation, and its appointed registration body processes all applications and manages registrations and acceptance. All data is sent to the National Life Prolonging Medical Care Administrative Authority and compiled which is shared among all hospitals and doctors.

Registration bodies such as hospitals and non-profit organizations are appointed to serve as assistants to the Administrative Authority to help patients with LW documentations and provide medical explanations.

When seriously ill patients do not have LWs, this registration body provides an opportunity for them to express and document their wishes regarding their life prolonging medical care plans.

Termination of life prolonging measures possible during the dying process

When the primary care physician and a specialty physician diagnose a patient as terminal ill with several months to live, the patient can request a medical plan to be documented. The physician explains the current medical situation and options, including termination of life prolonging measures. When it is mutually agreed, the medical plan is documented and signed by all parties.

Documentation of medical plan has another purpose. In Korea, palliative care is not advanced, therefore, when a patient requests it, medical providers must follow the documented medical service.



Picture of **Dr. Yoon-seong Lee** (Professor of Forensic Medicine, Seoul National University College of Medicine): As the Chairman of a special committee for National Bio-ethics Council, his recommendations became the basis of the new law three years ago.

He stated that reaching national unanimity in the area of bio-ethics was a significant accomplishment, as unanimity is not easily gained. This law provides everyone the opportunity to decide how to conclude one’s life. Society in which we can talk frankly about death will come soon.

The law only applied to cancer at first, but we have expanded it to cover HIV, chronic obstructive pulmonary disease and liver cirrhosis.

The timing to qualify for withdrawal or termination of life prolonging measure is not necessarily at the start point of terminal stage. This law specifies the time in which to qualify a patient with a medical condition in the dying process, which is defined as “imminently approaching death by a rapid decline of medical condition (several weeks in anticipation)”. Therefore, the law does not apply until the above timing is reached.

The life prolonging measures defined in this law are limited to cardio pulmonary resuscitation, blood dialysis, cancer medication, and artificial respirator. On the other hand, palliative care, artificial hydration and nutrition, and also oxygen supply by oxygen mask (not by machine) are specifically stipulated as not applicable to this law. The healthcare community opposed the exclusion of hydration and nutrition, but the socially influential religious leaders claimed that termination of hydration and nutrition causes starvation, which disgraces sacredness of life; therefore, this specific clause was added in the law.



Picture of **Dr. Jung Tongyoung**, Director, Division of Bio-ethics policy, Ministry of Health and Welfare: There were originally seven separate bills which were eventually combined into one, which successfully passed legislature. He was instrumental in the behind-the-scene persuasion of the opponents to vote unanimously. He is also a physician.

Dr. Tongyoung said that there will be many people unsatisfied with the restrictions of the bill, but the law legally permits termination of life prolonging measures. “Because of it, I believe the medical community finally accepts its contents.

Importance of patient’s self-determination and family’s judgement

Aside from the two tools for confirming a patient’s own wishes, one being the LW and the other being “life prolonging medical care plan,” this law stipulates two methods:

1. If the patient is incapable of making his/her own decisions, the consent of two or more family members will be regarded as his/her own wish. For example, family members’ statements that the patient often expressed his/her dislike for life prolonging measures, then that testimony will be honored and valid.
2. When the patient’s wish is not clear and he/she has never mentioned this topic, all of the family members’ agreed consent will be regarded as his/her own wish.

The definition of “family members” is spouse, immediate children, grandchildren and parents. If there aren’t any, siblings are considered family members.

As its name indicates, this is a combined law reflecting elements of both dignified death law and hospice law, which promote improvement of palliative care. This is in accord with religious belief against termination of life prolonging measures without full improvement of palliative care.



Picture of **Dr. Young Ho Yun**, Professor of Seoul National University College of Medicine (Family Medicine): He campaigned for parliament members to establish a coalition federation and founded the Hospice National Headquarters. His motivation to become a doctor was the death of his sister from stomach cancer when he was only a teenager.

He said that when hospice care is fully provided, this law will remain intact in the Korean society. “I would like to help make a culture in which the government and society provides compassionate and intimate care for all citizens as if they are all family members.”

Establishment of National “Hospice Day” and pursuit of higher level of terminal medical care

As the second Saturday of October is now the national Hospice Day, Ministry of Health and Welfare will plan for implementation and promotional schedule.

The new law which achieved national unanimity by setting aside controversial issues and including rigid restrictions, has generated some cynical results.

What started the movement of legalization was a medical-criminal lawsuit known as the Severance Hospital Case. An elderly woman known as “Grandma Kim” went into a persistent vegetative state after being admitted to the hospital. Her family claimed that she was always against having any life prolonging measures, and requested for the removal of artificial respirator. The hospital rejected the request, and the family eventually sued the hospital.

This case drew nationwide attention, and dignified death became a social issue. In 2009, Supreme Court ruled that withdrawal of life prolonging measures was legal, which made legislation of a bill to become an urgent agenda of the government.

If it was not for this lawsuit, the new law probably would not have existed. Ironically enough, the elderly woman, Kim, would not be able to remove her respirator because persistent vegetative state does not meet the qualification criteria of a medical condition with rapid decline, imminently approaching dying process. Needless to say, the medical community recognizes such negative aspects of this law.

Visiting Korea’s Society for Dying with Dignity

Korea’s Society for Dying with Dignity headquarters office is located in a small building in the city of Seoul. Ms. Hon Yanhi, the co-chairwoman who manages the organization’s daily operations, warmly greeted me with “We know all about Japan Society for Dying with Dignity.”

Like ours, the organization prepares and issues LWs, or advance directives for medical care, and campaigns for propagation and enlightenment of the LW. It was established 4 years ago and consists of about 100,000 members with registered LWs.

She showed me a sample of their one-page LW. For each of the three categories, brain damage, terminal illness, and natural death, there is a column to check, either “do want” or “do not want” life prolonging measure.

It lists different types of life prolonging treatment: vasopressor, cardio pulmonary resuscitation (CPR), artificial respirator, blood dialysis, etc. with a box to check either “do want” or “do not want” for each. At the bottom, there are signature blocks for the patient, two medical agents, and a witness.

Over 40 telephone consultation calls per day seeking registration appointments

We recommend patients to maintain the original copy of the LW in a safe place, and use a copy for the doctor. The organization also distributes free pocket sized cards indicating where the original LW is kept.

The fund for activities comes from government subsidy, donations from individual and organizational supporters. There is no fee or cost to the LW registrants.

Even during the interview, their phones were ringing constantly. An average of 40 calls are received every day from people wishing to make LWs. Telephone consultation seems to be one of the core pillars of the organization’s activities.

The organization’s LW form was developed by an associate professor, Dr. Yi Yiruhaku of Yonsei University School of Medicine. This university’s Bio-Ethics Policy Study Center developed a scientifically sound LW as part of its research topic for the first time in Korea. This LW was publicly introduced six years ago and received an astonishing response from society which recognized the importance of the LW.

This organization was established as a combined product of Bio-Ethics Policy Study Center and Ms. Hon’s Life and Death organization which is heavily influenced by Protestant teachings.

According to Associate Professor Yi, many groups such as hers supporting dignified death started a civil movement in the 1990’s. When the Severance Hospital Case sparked the public, the existing civil movement became large enough to cause a significant social impact.

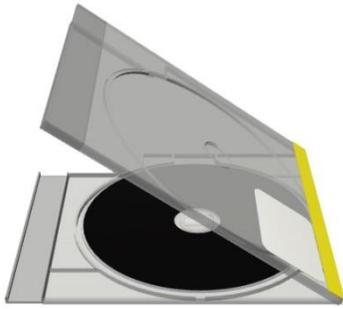
2016 Local chapter activities in the frontline

“Dignified death” added to medical school curriculum

Tokai Chapter provides support to Kawai Preparatory School in documentary production

Kawai Juku, a major and prominent preparatory school produced a documentary entitled “Ethical issues at the end of life aligned with dying with dignity.” Ms. H. Aoki, former president of Tokai Chapter and Mr. Y. Masuda, Director of Tokai Chapter, appear in the documentary.

Kawai Juku offers a unique curriculum including classes in palliative care, in-home medical care, and dementia, covering all issues of modern medical care to teach the students not to lose sight of the basic principles and purpose of medical practice as they tend to become preoccupied with college entrance examination preparation.



Ms. H. Aoki explains that “dignified death” defined by JSDD is a concept that a patient accepts and receives natural death by refusing meaningless life prolonging measures at his/her own will when medical conditions become incurable and terminal. As to legalization of “dignified death,” she emphasizes the absolute necessity for physicians’ immunity, as exemplified by the Sagamihara criminal case in which a mother removed her son’s respirator who was suffering from ALS. She gave her strong support to all physicians which she considers a selfless, demanding and life time occupation worthy of support.

Director Masuda expressed his wishes for students to become physicians who can put themselves in the patients’ shoes and truly listen to their needs. Some JSDD members also appear in this documentary expressing their motives for becoming members.

In the documentary, physicians also point out adverse outcomes of “dignified death,” as well as voices of strong opponents to give students from 26 schools nationwide all aspects of the issue for deep consideration.

Chugoku Chapter’s first LW symposium Aiming to trigger a boost of activities

Chugoku chapter held its first LW study forum on March 26 at in Izumo City, Shimane Prefecture (co-sponsored by Izumo In-home Care Study Group). The topic of the forum was “End of life and community total care, attended by approximately 50 people.

Chapter Director, Dr. Y. Matsumoto of Masuda city addressed the audience with a keynote. He emphasized the importance of patients’ self-determination by stating, “You own your life. Do not leave it to someone else. You have to make the decision.”

During the symposium, a midwife named Ms. Y. Kasebe talked about her experiences caring for her mother-in-law (98) at home.

Dr. T. Imada, Director of comprehensive Medical Department at Shimane Prefecture Central Hospital, talked about his involvement in setting up “Vivid life Day” (third Saturday of October) four years ago under the sponsorship of his hospital. On this day, people reflect on life and share their thoughts about life and death with their families.

Professor of Shimane University School of Medicine, Dr. Isobe reported that the university is now preparing advance directive documentation to be used at their university hospital. This document shows the treatments a patient wants or does not want in case he/she becomes incapable of making those decisions, including ten examples to be checked off, such as artificial respirator, nostril or central IV, stomach tube feeding, etc..

Izumo city, with 170,000 population, is now campaigning for “active service throughout life.” Professor of Shimane University School of Medicine, Dr. K. Shioaki is a leading member of the movement and a played a vital role in making this LW symposium a reality.

Director of Chugoku Chapter, Mr. F. Masaki said “We aim to increase the activity level in all corners of this region, and to start it in Izumo would hopefully become a trigger for other cities.”