

A message of gratitude for the workshop

I would like to express my sincere gratitude to Professor Fernando Vidal and Himeno Yukiko for once again hosting such a wonderful seminar.

Ann Johnson, Ana Santangelo, Lucia Denegri Mendez,

Nice to meet you. My name is Yumiko Kawaguchi.

I lost my mother to ALS. In 2003 I started Sakurakai to provide support for patients with LIS on ventilators, and I also run a separate helper dispatch business, which I continue to run to this day.

From 2006, I served as a director of the Japan ALS Association for 12 years.

As a researcher in the field, I am involved in policy and ethics research on ALS at Ritsumeikan University's Graduate School of Core Ethics and Frontier Sciences.

I wondered why so many ALS patients in Japan choose to use ventilators and survive for long periods of time, and investigated this from a social perspective, including the patient movement in Japan, and compiled my findings in my doctoral thesis in 2013.

Recently, I have become interested in a cultural anthropological approach, and I am interested in learning more about the psychology of people with LIS and ALS from different religious and cultural perspectives from that of Japan.

Today, thanks to the development of communication technology, I was able to listen to Ms. Himeno and Mr. Onda from Japan, and from Professor Vidal, Ms. Ana, Anne, and Lucia from Spain, all at once. I feel like I want to study the similarities and differences between LIS in Japan and Europe in more depth.

Like Onda-san, Japanese LIS people are very active and positive.

The medical and nursing care systems are well developed, so even if you are an LIS, you can do anything if you use a lot of helpers like your hands and feet. It has also become possible to work. Even LIS are active in society as company managers, investors, tax accountants, farmers, sake brewery master brewers, artists, dancers, and so on.

However, even so, each individual has serious worries and problems, and even if a system is in place, it is not enough to address the emotional pain of patients.

In order to learn more about assistive technology, I would like to hear from LIS persons and their supporters around the world.

Up until now, I have asked Rob to accompany me to international alliance conferences and act as an interpreter when making presentations. I have the opportunity to interact with people from patient groups overseas every year, and I have frequent contact with people from Korea and Taiwan in particular, but I have had almost no contact with researchers from Western countries.

Through the collaborative research of this group, we can propose how we should think about the important medical, nursing, and support skills that are common to LIS and people with ALS around the world, or about the way of life of LIS. Then, I expect that we will be able to create a wonderful movement.

Thank you for your continued support.

Yumiko Kawaguchi, Vice President, NPO ALS/MND Support Center Sakurakai