



Statement for Rare Disease Day 2020 in Japan

Statement by Yukiko Nishimura, RDD Japan Chief Secretariat/President ASrid

29 February 2020 TOKYO - Rare Disease Day (RDD) movement was started in Sweden in 2008, with the purpose of improving the quality of life of patients suffering rare and intractable diseases by promoting better diagnosis and care.

Japanese associations joined Rare Disease Day (RDD) in 2010. The RDD Japan secretariat office is located inside NPO ASrid, RDD Japan celebrated its 10th anniversary in 2019, and official events were held at 46 locations whole in Japan.

RDD 2020 in Japan official events were to be held at 53 locations nationwide. However, our activity was stagnant due to the outbreak of a new coronavirus (SARS-CoV2) in December 2019.

Usually, the date of RDD Japan local event is determined by the Local organizer between the beginning of February and the end of March of that year.

In 2020, the RDD local events were held smoothly until mid-February. At the Experts Meeting on Infectious Disease Control held by the Government of Japan on February 16, and they evaluated Japan as "early SARS-CoV2 outbreak". Following this announcement, the emergency response headquarters were set up in various places, and as a result, many events had to be restrained.

The definition of "Rare Disease Day" is only for the last day of February. However, many stakeholders and supporters around the world have been preparing for their activities for months. Given the feelings of the organizers who decided to cancel, my heart is bursting.

In Japan, the SARS-CoV2 turmoil continues today. Prime Minister Abe has requested elementary and junior high schools to be closed for several weeks, and teleworking style is recommended for companies. For rare disease and NANBYO (= rare disease/refractory disease/long-term chronic disease) patients who have symptoms, the spread of infection can lead to significant stress.

But we are connected in the RDD community. There is the Rare situation in a Rare year, however, we do not stop our activities. RDD Tokyo, the largest event in RDD Japan, will postpone the event scheduled for February 29 to Saturday, May 30, 2020. The content of the event will be exactly the same as before the delay. In addition, we will invite the RDD Japan local organizers from all over the country to the Tokyo event, and everyone will celebrate the RDD 2020 in Japan again.

Many local events are also postponed after April. We would like to respect the decisions of the organizer who has decided to cancel, as well as the decision of the organizer who wishes to postpone it by all means. Everyone in rare disease community worldwide, please understand our decision. And please continue to support the activities of RDD Japan.

Finally, on behalf of the Japanese RDD stakeholders, I send this word to the world.

"We sincerely bless RDD2020!"

