

# Rare Disease Day Activity in Japan ~Social awareness campaign by various organizers

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RDD JAPAN held its 10<sup>th</sup> anniversary in 2019  
→ RDD JAPAN Official events increased  
from 3 to 46 in the past 10 years

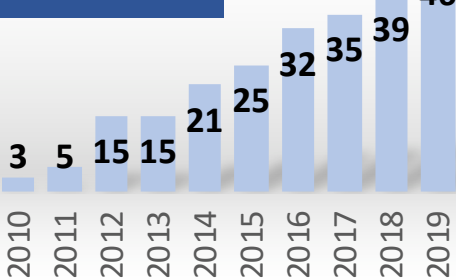
- Formation of community beyond diseases
- Active contribution by all stakeholders
- A valuable educational opportunity for the general public
- Creating a market where "patients' testimonial"
- Providing a wide range of expertise

RDD has created a new network in Japan

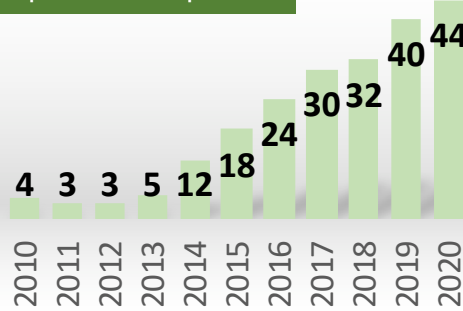
Agreements reached in the Secretariat before the first RDD

- Do not have a patient "only" meeting
- Create RDD Japan secretariat office and consolidate information in **All Japan system**
- Include **NANBYO** in the target disease of RDD
- Not only a place to learn but also a place to **enjoy**
- Always think about **continuation**

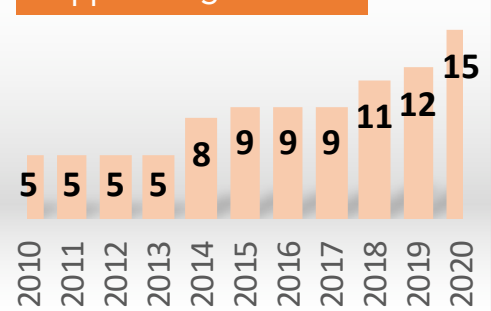
RDD Japan Official events



Sponsor companies



Supportt organization



## Participant's Voice



I am very impressed by the fact that the media was able to listen to such patients. 10 years ago, while there was little understanding of new drug development for ultra-rare diseases, it is surprising that it is now popular thanks to RDD. Society alone does not change with patients alone. And my illness alone does not solve the fundamental problem. RDD is a very valuable opportunity and place.  
*Patient, RDD 2019 Press seminar*

A day where everyone feels connected. I think that's the RDD.

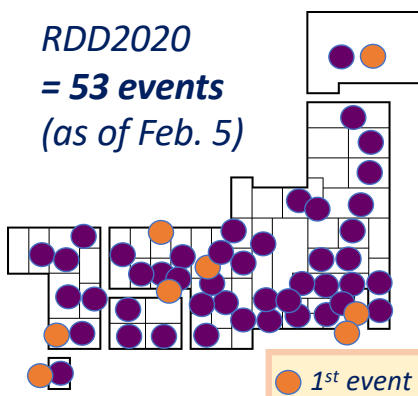
*RDD2019 participant (pharmaceutical company employees)*

The RDD is already well established in this area. Not only do I learn about the existence of intractable diseases, but I also learn a lot from being able to talk to the people involved.

*RDD2020 participant (city councillor)*

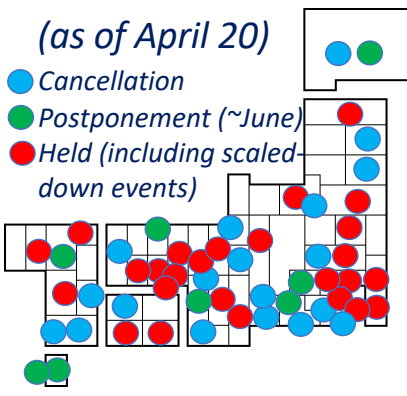
## The Eleventh Year Tribulation (COVID-19 crisis)

RDD2020  
= 53 events  
(as of Feb. 5)



(as of April 20)

- Cancellation
- Postponement (~June)
- Held (including scaled-down events)



-In Japan, RDD is the "common slogan."  
-RDDs create a "patient-told" market  
-Further revitalization of the new community



RDD JAPAN