



NPO ASrid
President: Yukiko Nishimura
contact@asrid.org

News Release

May 10, 2025

Hosting of the Osaka-Kansai Expo Event: “Rare and Intractable Diseases — Step Forward Together (RDD x NANBYO Day Collaboration)” Let’s Think Together, Joyfully and Inclusively – RDD x NANBYO Day

- *A collaborative event between RDD (Rare Disease Day) and NANBYO Day will be held at the Osaka-Kansai EXPO venue.*
- *The only public event focused specifically on “NANBYO (rare and intractable diseases)” in the EXPO.*
- *Scheduled on Friday, May 23, commemorating the enactment of Japan’s NANBYO Law*

We are pleased to announce the upcoming Osaka-Kansai Expo event: “Rare and Intractable Diseases – Step Forward Together (RDD x NANBYO Day Collaboration): Let’s Think Together, Joyfully and Inclusively.”

The field of rare diseases encompasses diverse communities formed by patients, families, and stakeholders. In 2016, an NGO Committee for Rare Diseases was established within the United Nations, followed by the adoption of a rare disease resolution at the UN General Assembly in December 2021. Additionally, Rare Disease International (RDI), a global patient organization, was officially recognized as a WHO collaborating organization in May 2024.

Rare Disease Day (RDD), the world’s largest awareness campaign aiming to improve the quality of life (QOL) for people with rare and intractable diseases through better diagnosis and treatment, is supported by these international organizations. In Japan, the RDD secretariat is hosted by NPO ASrid, with 2025 marking the 16th anniversary of RDD Japan.

The World EXPO is highly significant for the rare disease community. At Expo 2020 Dubai (2021–2022), EURORDIS, which hosts the global RDD secretariat, organized the “Global Rare Disease Day Event” on RDD’s designated date, February 28, 2022.

However, the Osaka-Kansai EXPO 2025 does not fall in February. Therefore, Japan will mark its international contribution by hosting this event on May 23, recognized domestically as NANBYO Day, commemorating the enactment of the Act on Medical Care for Patients with Intractable/Rare Diseases on May 23, 2014. Since 2015, national patient councils have hosted events annually to raise awareness around this day.

This event will be Japan’s first rare disease-themed EXPO event organized by patients, families, and supporters. Collaborating partners include the RDD community, officially registered organizers and companies in the Kansai region, the Japan Patients Association (JPA), and junior and senior high schools that host RDD events.

We aim to present and reflect on the present and future of rare and intractable diseases — both in the context of Japan’s national NANBYO policies and global initiatives — and to inspire action. The event

will also feature a range of entertainment, jointly delivered with patients, families, and supporters.

We are honored to announce that Her Imperial Highness Crown Princess Akishino is scheduled to attend the event.

We warmly welcome participation from all.

Event Details

Date & Time: Friday, May 23, 2025 — 1:00 PM to 6:00 PM (Doors open at 12:00 PM)

Venue: Osaka-Kansai Expo Site, Festival Station [Stage Area]

(Yumeshima, Konohana Ward, Osaka City, Osaka 554-0000)

Featured Speakers (in order of appearance):

- Eiichi Omura: Former Japan Aerobic Gymnastics Representative, Person living with Type 1 Diabetes
- T-STONE: HIP-HOP Artist, Person living with Type 1 Diabetes
- Durhane Wong-Rieger: Chair of RDI / President & CEO of CORD (Canada)
- Ruth Kuan-Ju Chen: Executive Director, TFRD (Taiwan)
- Yukiko Nishimura: Chief Secretariat of RDD Japan / President, ASrid
- Keita Otsubo: Secretary-General, JPA
- Tomoya Oshiki: Assistant Director, Intractable Disease Control Division, Ministry of Health, Labour and Welfare
- Shingo Fukushima: Executive Director, National Network for Children with Intractable Diseases
- Hiroshi Oguro: Director, Osaka Intractable Disease Support Center
- Ayako Ozawa: Person with Muscular Dystrophy
- Mamiko Sakaida: Soprano singer, Person with Neuromyelitis Optica
- Yusuke Okuno: Guitarist, Supporter
- KICK: Dancer, DIVERz, Supporter
- Rino Ishii: Pianist, Supporter
- RDD host organizations from the Kansai region
- Junior and senior high school RDD participants (Osaka Meisei Gakuen, Osaka Jogakuin, Nada High School)

Event listing on EXPO site:

<https://www.expovisitors.expo2025.or.jp/events/3350c404-d575-4396-8040-7273df4b06ba>

Program details:

<https://rddjapan.info/2025/expo/>

About Rare Disease Day (RDD)

Rare diseases are defined by their low prevalence and complex pathophysiology, often resulting in delayed treatment or drug development. Rare Disease Day (RDD) began in Europe in 2008 and has since expanded to over 100 countries. Japan joined in 2010 with the first event held in Tokyo and has grown steadily.

Participants include patients, families, healthcare providers, drug developers, researchers, and the general public. RDD is gaining recognition as a key initiative that bridges rare disease communities with society.

For more, visit the RDD Japan 2025 website: <https://rddjapan.info/2025/>

About ASrid

NPO ASrid (Advocacy Service for Rare and Intractable Diseases' multi-stakeholders in Japan) is a cross-disciplinary, cross-sector nonprofit that connects patients, families, and stakeholders as a neutral

intermediary. It supports collaboration and creates new value/services in the rare and intractable disease field under the slogan: “To Patients, For Patients, Beside Patients.”

Founded in 2014 as a humanities-based startup out of the University of Tokyo, ASrid is led by researchers and experts from various fields.

ASrid emphasizes the importance of delivering Patient-Reported Outcomes (PRO) to relevant stakeholders in appropriate ways. Its activities span research, international partnerships, and public awareness events, working collaboratively with patients, healthcare professionals, researchers, industry, and government. Patients and families are also included as active members.

For more, visit: <https://asrid.org/>

For inquiries regarding this press release:

Contact: NPO ASrid Osaka EXPO Secretariat

Address: Sunrise Hongo 4F, 5-30-20 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan

Email: contact@asrid.org

(Attn: Yukiko Nishimura, Secretariat Director, Osaka EXPO Secretariat)