

# **RE (ACT) CONGRESS and IRDiRC CONFERENCE**

**Online on 13–15 January 2021**

## **We amplify collective action for research on rare and orphan diseases #RAREvolution**

The sixth edition of the RE(ACT) Congress and the fourth edition of the IRDiRC Conference were held online in a first-time joint event on 13-15 January 2021, organized by the [BLACKSWAN Foundation](#) in collaboration with [IRDiRC](#), International Rare Diseases Research Consortium, and [EJP RD](#), European Joint Programme on Rare Diseases. The congress also benefited from the support of Rare Diseases International (RDI) and EURORDIS.

The event attracted around 300 attendees, including scientists, physicians, patient organizations, pharmaceutical industry representatives and start-ups, patients, and other international stakeholders. During the three-day conference, world-class speakers, panelists, and participants shared their vision, experiences and presented their innovative and outstanding scientific research on rare diseases. The full list of speakers and panelists is available at <http://www.react-congress.org/speakers/>.

The conference presented the latest advancements in knowledge, understanding, and innovation in rare diseases research and offered an expanded view onto health systems for rare diseases.

Focused sessions addressed new tools and technologies for diagnosis, progress, and challenges in advanced therapies for rare diseases, innovative approaches for clinical trials for ultra-rare diseases, and methodologies to measure the impact of rare diseases diagnosis and treatments.

Emphasis was given to the barriers to access to approved therapies and treatments to patients as drivers in drug development and clinical trials. A hands-on workshop on the IRDiRC Orphan Drug Development guidebook and a rare diseases foresight session from across different areas of the globe completed the program.

Each session was followed by a panel discussion involving the speakers and one or more patient representatives, providing deep insights as fundamental and indispensable actors along the whole diagnostic and therapeutic path.

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