

ECRD 2022



Review of the 11th European Conference on Rare Diseases and Orphan Products 2022

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THE 11th European Conference on Rare Diseases (ECRD), partner organisation of the EURORDIS-Rare Diseases Europe, is the largest patient-led rare disease policy event. The fully virtual conference took place from 27th June to 1st July 2022 and saw over 1,000 attendees, including patient advocates, policymakers, researchers, clinicians, healthcare professionals, healthcare industry representatives, academics, payers, regulators, and member state representatives. Guests were invited to attend sessions and discussions across 5 days from over 100 speakers, panellists, and chairs.

The conference allows for collaborative dialogue, learning and conversation, the shaping of goal-driven rare disease policies, and for important and innovative discussions on a national and an international level to take place. The conference is an unrivalled opportunity to network and exchange invaluable knowledge with over 1,500 stakeholders in the rare disease community with worldwide contribution.

The ECRD scientific programme was notably inclusive and sustainably responsible, and the event days were dedicated to discussions on how to reach three visionary goals for people living with a rare disease. The three goals are aligned with the United

Nation's (UN) Sustainable Development Goals, and were inspired by the Rare 2030 project. They include ensuring healthy lives and promoting wellbeing for all people living with a rare disease at all ages; reducing inequalities for people living with a rare disease; and building resilient infrastructure, promoting inclusive and sustainable industry, and fostering innovation for people living with a rare disease.

Rare 2030 was a pivotal 2-year foresight study, supported by the European Parliament and European Commission (EC), that guided a large-scale and multistakeholder reflection on rare disease policy in Europe through 2030. The concluding recommendation of Rare 2030 was the need for a new European policy framework on rare diseases with measurable and actionable goals, given that current actions at member state level alone, or legislative changes in specific areas, are not enough. Moving forwards in a post-COVID-19 world will require the adoption of collective strategies at the European level that facilitate the implementation of policy coherence and mutually reinforcing activities across Member States.

The closing plenary session on the final day of the conference reminded participants that rare diseases must be addressed globally, across and beyond



Europe. The audience were given a clear call to action in the immediate, medium, and long-term future.

This year's ECRD provided a unique opportunity for patients, practitioners, and other stakeholders to not only reflect on recent policy recommendations, but also engage in an open and supportive dialogue with the aim of generating high-quality and concrete action plans. This represents a crucial step in tackling the unmet medical needs and complex challenges experienced by people living with a rare disease in Europe. ●

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