

THE 10th EUROPEAN CONFERENCE ON
RARE DISEASES & ORPHAN PRODUCTS



ONLINE on 14-15 May 2020

THE JOURNEY OF LIVING WITH
a RARE DISEASE in

2030

ECRD 2020 Online - Communications Toolkit

The European Conference on Rare Diseases & Orphan Products (ECRD) is recognised globally as the **largest, patient-led rare disease event**.

ECRD 2020 will take place **uniquely online** from 14-15 May.

Use this communications toolkit to encourage your contacts to register for ECRD!

People living with a rare disease have the right to reach their highest potential of well-being. Join ECRD 2020 online to take part in discussions to inform and build the future ecosystem for rare disease policies and services.

The Conference is an unrivalled opportunity to network and exchange invaluable knowledge with **all stakeholders** in the rare disease community from around the world: patient representatives, policy makers, researchers, clinicians, industry representatives, payers and regulators.

Why now? As the EU shapes its future policy and spending frameworks for the coming decade, ECRD 2020 serves as an opportunity to co-create policy options today that can lead to a better patient journey for the years ahead.

10th 

ONLINE on 14-15 May 2020

Hundreds of attendees



including patients' representatives,
academics, healthcare professionals,
industry payers, regulators and
policy makers



2 days

14-15 May 2020



Worldwide Participation

ECRD2020



Over 100
expert chairs,
speakers and
panellists



How you can communicate about ECRD 2020 online

Help us spread the word that ECRD is taking place online and that more people than ever can participate from their homes!

Below are some useful **communications tools** for your social media channels, newsletters and website (all accessible via the [Communication Tools](#) google folder and specific links below) :

- [ECRD visuals](#) (including [email signature](#), [banner/header](#) for websites and newsletters, graphics optimized for [Facebook](#), [Twitter](#), [LinkedIn](#) and [Instagram](#))
- [ECRD 2020 6 Parallel Themes visual](#)
- [Photos from past events](#)
- [Infographic snapshot](#)
- [Word cloud image](#) "What does ECRD mean to you?"

Social Media

- [Social media Toolkit](#) (including prepared social media posts you can share)
- [Social media visuals](#) (some finished + some editable)

Key dates you can communicate about ECRD 2020:

- [Registration IS OPEN](#): Until **1 May**
- **FREE pre-conference webinar on the Rare2030 Project**: 23 April, 13.00 – 14.00 CEST. [Webinar Registration is now open](#). The webinar is free for all conference attendees to hear the latest outcomes of the Rare2030 Foresight Study and understand how the study lays a foundation for policy discussions at the conference.

Please note: all timings advertised in the ECRD programme are CEST (Central European Summer Time).

ECRD 2020 online – messaging for your communication

ECRD 2020 moves online!

With ECRD taking place online, it is now possible for more of you than ever before to [register to participate online](#) from wherever you are in the world.



Why participate in ECRD 2020 online?

- Using the online platform you can participate in the ECRD from the **safety and comfort of your own home**.
- Direct from your desk - participate in **sessions run by industry experts** built around a fully developed programme with [six themes](#). **Over 100 speakers** will lead online, interactive sessions and be available to answer questions.
- [Registration fees have been revised](#) to make it easier for you, your friends and colleagues to participate. **A great opportunity for your teams currently working from home** to still be able to participate in an event.

Features of ECRD 2020 online:

- A more flexible conference! You will now be able to **switch between parallel sessions** and access recordings of all sessions for up to a year after the conference.
- The online platform is being built to guarantee **online networking opportunities** with speakers and fellow conference participants.
- Access to the **ECRD posters and exhibitions** online. Use interactive games, quizzes and badges to make connecting from your home or office more fun.

ECRD 2020 overarching theme & six parallel themes

The journey of living with a rare disease in 2030

The rare disease community has made great strides towards improving diagnosis, care and treatment for people living with a rare disease in recent decades, but without vigilance and constant effort, progress can easily be reversed. The health of 30 million people living with a rare disease in Europe should not be left to luck or chance.

The ECRD 2020 theme “**The rare disease patient journey in 2030**” recognises that the next decade holds great potential for improvement and that while **we cannot predict the future, we all have a role in preparing for it**. [See the full ECRD programme](#) built around these six parallel themes:

1. **The future of diagnosis: new hopes, promises and challenges**
2. **Our values, our rights, our future: shifting paradigms towards inclusion**
3. **Share, Care, Cure: Transforming care for rare diseases by 2030**
4. **When therapies meet the needs: enabling a patient-centric approach to therapeutic development**
5. **Achieving the triple A's by 2030: Accessible, Available and Affordable Treatments for people living with a rare disease**
6. **The digital health revolution: hype vs. reality**