

European Conference on Rare Diseases & Orphan Products 2020 moves online

12 March 2020, Paris – In the context of the current COVID-19 pandemic and in line with WHO guidelines, the upcoming [European Conference on Rare Diseases & Orphan Products](#) (ECRD) will now **take place online** on 14-15 May.

The health and safety of all stakeholders participating in ECRD, including people living with a rare disease and their carers, is our primary concern.

EURORDIS-Rare Diseases Europe is keen to move the conference online in order to maintain the planned dates. 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.

The ECRD brings together over 800 participants from 50 countries. Using an innovative online platform, more people from anywhere in the world will now be able to attend from the safety of their home or office, benefiting from the rich content of a fully developed programme built around [six themes](#). Over 100 speakers will lead online, interactive sessions and be available to answer questions. Features of the online platform will include the flexibility to move between parallel sessions, online networking opportunities and a poster display. EURORDIS is working to build an online conference that is a unique and engaging experience.

EURORDIS thanks ECRD partners, particularly co-organisers Orphanet and host national alliance Rare Diseases Sweden, for their full support in reaching this solution.

To note:

- ***The price structure of fees to attend ECRD online will be revised to reflect the change in event format. If you have already registered, you will receive information regarding a reimbursement of the difference in cost for registration.***
- ***Details of updated fees and how to participate online in the ECRD will be made available via rare-diseases.eu and by email to participants that have already registered.***
- ***Anyone who has reserved a hotel through the ECRD official website can contact ecrd-housing@meetagain.se directly to claim a reimbursement by **1 April**.***

At the start of this new decade, and as the ongoing [Rare 2030 foresight study](#) will come to completion at the end of this year, the time is now to shape the future for people living with a rare disease. 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.

Thank you for your solidarity.

Note for EURORDIS members: The EURORDIS Annual General Assembly will now also take place online. Information on how to participate online will be sent directly to you in the coming weeks.

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To register to participate in ECRD 2020

Please visit: www.rare-diseases.eu/register/

Contacts

For questions regarding registration at ECRD:

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Sources of information on COVID-19

Members of the rare disease community may be concerned about their health. Please find below links to official information sources regarding the COVID-19 pandemic that are updated regularly:

- [World Health Organization](#)
- [European Centre for Disease Control](#)
 - [National information resources for the public on COVID-19](#)
- [US Centers for Disease Control and Prevention.](#)

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 894 rare disease patient organisations from 72 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

About the ECRD

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

Leading, inspiring and engaging all stakeholders to take action, ECRD is where innovative solutions in the rare disease field are born. The Conference is an unrivalled opportunity to network and exchange invaluable knowledge with all stakeholders in the rare disease community from over 50 countries around the world - patient representatives, policy makers, researchers, clinicians, industry representatives, payers and regulators.