



Rare Diseases 360°  
Collaborative Strategies to leave no-one behind

9th European Conference on Rare Diseases & Orphan Products  
10-12 May 2018 Vienna

#ECRDVienna

## EURORDIS calls for new EU rare disease policy framework at ECRD 2018 Vienna

11 May 2018, Vienna – On the opening day of the [European Conference on Rare Diseases & Orphan Products 2018 Vienna](#) (ECRD), EURORDIS-Rare Diseases Europe, an alliance of nearly 800 rare disease patient groups and organiser of the conference, is calling for a new EU policy framework and strong drive from the EU institutions in the area of rare diseases.

Over the last 20 years, breakthrough legislation and policy on rare diseases and orphan medicines have been driven by the rare disease patient community and EU institutions, with a strong leadership from the European Commission (EC). It is widely recognised that rare diseases is an area with **high European added value**, for which the most effective strategies are cross-border and EU-wide. The EU Regulation on orphan medical products and the European Reference Networks (ERNS) are some of the many successful EU policies that improve the lives of the 30 million Europeans living with a rare disease.

Next steps in EU rare disease policy, including the adoption of a **European Joint Programme Co-Fund for Rare Diseases** in 2019, which will structure rare disease research, and the possible adoption of the current legislative proposal for **European cooperation on health technology assessment**, will have a positive impact on the delivery of rare disease treatments.

### EU rare disease policy needs new drive for next 20 years

Great progress has been made over the last 20 years. However, since the dismantlement of the EC expert group on rare diseases, and with no plans for a future joint action on rare diseases, it seems the **EU rare disease policy structure is under review**. Yet, **great challenges still remain** for the majority of patients, for example in **accessing a diagnosis and treatment**, while **social care is still fragmented**.

Remarkable technological and scientific advances have led to an exponential increase in novel technologies and therapies on the market. These new opportunities embody hope for patients, but in parallel bring about concerns in terms of **access and of sustainability for health budgets**.

Moving forward, ERNs also need to be firmly anchored into national healthcare systems and integrated into revamped national rare disease strategies **to ensure individual patients can easily access the specific healthcare pathway they need**.

In order to address this evolving situation, and at a moment when certain EU policy actions are being discontinued, **it is in fact a time to grow EU actions** that will support and foster national actions and the EU citizens affected by rare diseases over the next 20 years.

**Yann Le Cam, Chief Executive Officer of EURORDIS**, commented, “We need to accelerate the momentum we have built over the last 20 years and create a new impetus to face emerging challenges and ensure no one is left behind. ECRD Vienna 2018, the largest multi-stakeholder gathering in Europe for the rare disease community, is an opportunity to discuss and reach solutions on how we can look to the future.”

He added, “We need to continue looking for these solutions at a supranational level to help to improve equity of access to health, and achieve universal health coverage and the health-related UN Sustainable Development

Goals. EURORDIS is calling for a strong drive from the EU institutions and in particular, a reaffirmed leadership from the European Commission in the area of rare diseases.”

## Next steps

EURORDIS has formed a working group of rare disease national alliances in Europe that is identifying priorities for future rare disease policy in the areas of codification, research, treatments, diagnosis, social care and policy, and more. Participants at ECRD 2018 Vienna will also be invited to vote to choose their main priorities for future rare disease policy.

EURORDIS also hopes to contribute to the EC information report to the Council of the EU on 10 years of achievements following the Council Recommendation on an action in the field of rare diseases (2009).

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## Press contact & interviews at ECRD 2018 Vienna

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## The European Conference on Rare Diseases & Orphan Products 2018 Vienna

The 9<sup>th</sup> edition of the [European Conference on Rare Diseases & Orphan Products](#) (ECRD) takes place from 10-12 May in Vienna. Organised by EURORDIS-Rare Diseases Europe, co-organised by [Orphanet](#) and [DIA](#), and hosted by the Austrian national alliance for rare diseases [Pro Rare Austria](#), ECRD 2018 Vienna is the largest multi-stakeholder gathering in Europe for the rare disease community.

Over 800 participants from across the rare disease field and more than 100 speakers are together to participate in sessions held under the main conference theme of "Rare Diseases 360° – collaborative strategies to leave no one behind". ECRD Vienna 2018 is an opportunity to discuss and reach solutions on how we can **look to the future** to improve the lives of the estimated 30 million people living with a rare disease in Europe and 300 million worldwide.

Focusing on [six themes](#), participants at ECRD will discuss and set out next steps on how to shape better research, policies and services that improve patients' access to the best possible medicines, healthcare and social policies and services.

Watch the opening and plenary session of ECRD 2018 Vienna online via [rare-diseases.eu/live](http://rare-diseases.eu/live), follow the conference via [#ECRDVienna](#), and see the full programme at [rare-diseases.eu](http://rare-diseases.eu).

## EURORDIS-Rare Diseases Europe



[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 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. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#).

## Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.