Rare disease community appeals to EU & member states to move into a new era of collective decision making in health

14 May 2020, Paris - Today is the opening day of the 10th European Conference on Rare Diseases & Orphan Products. Conference organiser EURORDIS-Rare Diseases Europe and co-organiser Orphanet are appealing to the EU and member states to step up efforts to put in place common actions across EU policies that will advance the health and wellbeing of people in Europe.

As is the case for COVID-19, there is a clear twofold added value to grouping efforts at the EU level in order to tackle rare diseases. First, to improve the health outcomes of the 30 million people living with a rare disease in Europe. Secondly, to minimise the impact on, and maximise potential return for, the economy/ies of the EU and member states.

People living with a rare disease already know so well the lessons that communities around the world are now being forced to learn as a result of the COVID-19 pandemic. Coronavirus aggravates their health, social, economic vulnerabilities in both the short and long term.

> **Yann Le Cam, Chief Executive Officer, EURORDIS**, commented, "We must quash this egocentric rhetoric emerging in some countries. It fragments Europe into diverging national-level decisions. We must combine our capacities and power at the European level, to ensure health, equity and solidarity for every individual citizen. We appeal to national governments and the EU institutions wherever possible to increase efforts in the coming year and decade to collaborate across the board on relevant EU policies that will strengthen healthcare systems."
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> He added, "There are many actions that the EU can take - invest in research and innovation… Adopt legislations enhancing competitiveness and addressing unmet medical needs… Expand and consolidate the European Reference Networks… Create a structured EU approach to ensure sustainable access to orphan medicines and new transformative gene/ cell therapies for patients, to name but a few. A lack of EU coordination is both detrimental to the health of people living with a rare disease and has an unnecessary negative impact on the economy."

> **Ana Rath, Director, Orphanet**, commented, "Now more than ever, the EU has a vital role to play in improving the health of its citizens. ECRD 2020 focuses on how to build policies and services over the next decade that will improve the journey of living with a rare disease for patients and families. The conference builds on the work of the ongoing Rare2030 Foresight study, which will conclude next year with a comprehensive set of key recommendations to policy makers on how to improve rare disease policy."

The resilience, courage and commitment of the people living with a rare disease, their families and their healthcare professionals will not be enough to overcome the challenges created by the pandemic. The power the EU and member states have when acting together should be used to negotiate collectively and generate investment. EU collaboration on research, health technologies, and healthcare is vital to tackle the types of health and economic challenges that know no borders.

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About the European Conference on Rare Diseases & Orphan Products 2020

The ECRD is recognised globally as the largest, patient-led rare disease event. Leading, inspiring and engaging all stakeholders to take action, the Conference is an unrivalled opportunity to network and exchange invaluable knowledge with **all** stakeholders in the rare disease community - patient representatives, policy makers, researchers, clinicians, industry representatives, payers and regulators.

ECRD 2020 takes place exclusively online 14-15 May. Discussions at the conference will go towards informing and building the future ecosystem of rare disease policies and services. For more information visit: www.rare-diseases.eu/.

About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 900 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 Orphanet

Orphanet is a unique resource, provide high-quality information and data on rare diseases, contributing to improving the diagnosis, care and treatment of patients with rare diseases.

Orphanet maintains the Orphanet rare disease nomenclature (ORPHAcode), essential in improving the visibility of rare diseases in health and research information systems.

Thanks to its network of 40 countries, Orphanet aims at orienting patients and doctors to the relevant expert resources, in Europe and beyond.

About 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. 72% of rare diseases are genetic whilst others are the result of infections (bacterial or viral), allergies and environmental causes, or are degenerative and proliferative. 70% of those genetic rare diseases start in childhood.

Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offerings 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.

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