Declaration on rare diseases launched at conference held by Maltese Presidency of the EU Council

21 March 2017, Valletta, Malta – EURORDIS-Rare Diseases Europe warmly congratulates the Maltese Presidency of the EU Council for bringing rare diseases to the top of the EU agenda.

At today's Conference on the Development and Access of Medicines for Rare Diseases, held by the Maltese Presidency of the Council of the EU and the Malta Medicines Authority, participants recognise the need for structured, voluntary cooperation between EU Member States to improve rare disease patients' access to better diagnosis, care, therapies and technologies.

On this momentous day, with the rare disease community at large represented, EURORDIS launches a Declaration calling for improved mechanisms of structured cooperation across EU Member States to address the unmet needs of people living with a rare disease.

The Conference is held in collaboration with the National Alliance for Rare Diseases Support Malta, the Marigold Foundation, E-Rare, EURORDIS, the Innovative Medicines Initiative and RD-Action.

A delegation of European patient representatives are also in attendance.

The Declaration focuses on three key areas:

> ### 1. Structured cooperation in healthcare for rare diseases
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> EURORDIS particularly welcomes the establishment of 24 new **European Reference Networks** (ERNs) as a point in history that will revolutionise patients' access to high quality care by connecting patients, experts and hospitals.
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> Attendees at today's conference recognise that the highly specialised care needed by rare disease patients, and which will be delivered through the ERNs, can only be delivered by **appropriately trained professionals**, and that such a qualified health workforce often needs to be trained **across borders**. In addition, to ensure their success, participants are calling for the full **integration of ERNs into national healthcare systems**.

> ### 2. Structured cooperation in research for rare diseases
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> Rare disease research has increased and improved over the last 10-15 years. It is recognised that cooperation in the field of research can bring about significant results, as shown by voluntary initiatives such as E-Rare or IRDiRC.
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> However, in order to deliver significant long-term results that have a positive impact on the lives of people affected by rare diseases, the rare disease community demands increased collaboration with **longer-lasting and integrated support for rare disease research**.

> ### 3. Structured cooperation for improved access for patients to therapies and innovative technologies
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> Participants at the Conference today recognise that there has been a sharp increase in the interest of Member States in new cooperative initiatives aimed at improving patients' timely and appropriate access to therapies and innovative technologies.
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> We believe that now is the time to consolidate these initiatives into a structured European approach, which fast tracks R&D, brings down the costs of medicines development and increases productivity to deliver more affordable treatments.
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> EURORDIS also supports proposals discussed today for a **European approach to collaborative medicines procurement strategies**, which could bring together a group of willing national or local pricing and reimbursement authorities from Member States, and could be implemented with the active participation of the European Commission. **We encourage public authorities in all Member States, and particularly the 22 Member States with a population of less than 20 million, to consider this proposal.**

The Conference takes place the day after an informal meeting of health ministers from EU Member States (watch the meeting's press conference), as well as the day after a parallel session entitled "Integrating Research and Healthcare for Rare Diseases: A structured cooperation with high community added value".

Hosted by the Malta Medicines Authority, EURORDIS, RD-Action and E-Rare, this parallel session offered the opportunity to explore synergies within and across the rare disease research and healthcare communities. Participants focused specifically on the infrastructural potential of European Reference Networks as a hub for the development of rare disease research, on the proposal for a European Joint Programme Cofund for rare diseases, and on other solutions for integrating research and healthcare activities in a sustainable way.

Speakers included Michelle Muscat, Spouse of the Prime Minister of Malta and President of the National Alliance for Rare Diseases Support Malta and Yann Le Cam, Chief Executive Officer of EURORDIS, as well as representatives from the European Commission, RD-Connect, BBMRI-ERIC, Orphanet, IRDiRC, E-Rare, and the JRC-EU Platform on Rare Diseases Registration, among others.

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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. For more information, visit www.eurordis.org

Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone. 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.

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