



Health ministers strengthen European collaboration on rare diseases

EURORDIS-Rare Diseases Europe welcomes EU Council conclusions on Member State cooperation between health systems and calls for concrete next step to improve patients' access to innovative medicines and specialised healthcare

16 June 2017, Brussels - EURORDIS congratulates the Maltese Presidency of the Council of the EU for [conclusions](#) adopted today that encourage Member State-driven voluntary cooperation between health systems.

The conclusions identify rare diseases as an area that can particularly benefit from such cooperation as a means to improve rare disease patients' access to innovative medicines and specialised healthcare through European Reference Networks (ERNs) and other policies.

EURORDIS is pleased that today's conclusions set the tone for the Council's future support of such cooperation. Action now needs to be taken to ensure that a new comprehensive approach to structured cooperation becomes a reality.

EURORDIS therefore supports the call on the European Commission to provide an update on the implementation of the 2009 [Council recommendation on an action in the field of rare diseases](#). Such an assessment can form a concrete basis, upon which next steps can be taken to build structured cooperation between Member States.

Yann Le Cam, Chief Executive Officer at EURORDIS, commented, "By building structured cooperation between Member States we can ensure that rare disease patients will have improved access to the both the medicines and specialised healthcare they need. The current discussion initiated by the Maltese Presidency on structured voluntary cooperation represents a timely opportunity to set in motion a process that could lead to the development and adoption of **a new policy framework for action on rare diseases at a European level**".

The Maltese Presidency has prioritised rare diseases throughout its presidency. A [declaration](#) launched by EURORDIS at a conference held in March by the Maltese Presidency called for structured cooperation between Member States in **healthcare, research** and for improved **access to therapies** for patients.

Momentous scientific developments, such as next-generation sequencing and genome editing techniques, have generated a brand new landscape for diagnosis and treatment development. The expansion of information technologies has unlocked the potential for improved and more cost-effective knowledge sharing processes and networking opportunities for healthcare providers, researchers and other disease experts, which will materialise in the ERNs.

However, with growing opportunities come new challenges of an ethical, social and financial nature that require an adapted and revamped policy framework. Moreover, not all needs are addressed: rare disease patients and their families still experience scarcity of medical knowledge, difficulties in accessing care and medicines, isolation from society, and often economic instability, among many other challenges. Today's financially challenged healthcare systems are not equipped to face the existing challenges. **Structured cooperation is therefore needed to tackle such challenges that prevent rare disease patients' access to better diagnosis, care, therapies and technologies.**

Notably, cooperation amongst Member States is vital to address the fragmentation of the market and reimbursement structure, the real obstacle to patients' access to therapies for rare diseases, rather than the system of incentives or the regulatory framework. We welcome therefore the call for a holistic assessment of the *'impact of incentives on innovation, availability, accessibility and affordability of medicinal products, including orphan drugs'*, whilst recalling that the current system of incentives has created a market for orphan drugs, with over 135 new rare disease therapies having become available since the landmark EU Regulation on Orphan Medicinal Products (1999).

EURORDIS welcomes and looks forward to opportunities to collaborate with the European Commission and Member States on all areas in the conclusions relevant to rare diseases.

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Notes for editors

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](https://twitter.com/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.