



## **EURORDIS welcomes the final adoption by the Council of the European Union of the Council Recommendation on European Action in the field of Rare Diseases**

Paris – 9 June 2009 - A European strategy that calls upon Member States to implement **national plans for rare diseases**, before the end of 2013, was adopted by the Council of Health Ministers of the EU today.

The Council Recommendation is important because it calls for concerted action at EU and national level in order to:

- Ensure that rare diseases are adequately **coded and classified**
- Enhance **research** in the field of rare diseases
- Identify **Centres of Expertise** by the end of 2013 and foster their participation into **European Reference Networks**
- Support the **pooling of expertise** at European level
- Share assessments on the clinical added value of **orphan drugs**
- Foster **patient empowerment** by involving patients and their representatives at all stages of the decision-making process
- Ensure the **sustainability** of infrastructures developed for rare diseases

This adoption marks the culmination of a series of legislative declaratory acts which have paved the way towards the recognition of rare diseases as a public health priority and as an area of unique European added-value for Community action.

EURORDIS has been at the centre of this process, voicing the patients' demands for a European policy framework for rare diseases, every step of the way. Starting with the successful *Public Consultation on Rare Diseases* in November 2007, followed by the adoption of the *Commission Communication on Rare Diseases*, in November 2008 and today the adoption of a *Council Recommendation on a European Action in the field of Rare Diseases*, each step has demonstrated the vital importance of EU action, as well as cooperation between Member States.

The Council Recommendation represents an important milestone for rare disease patients all over Europe. Its adoption means that patient representatives will be increasingly involved in the rare disease strategies of each Member State and be able to monitor the implementation of key issues which are important to patients, namely support for the social dimension of care and funding for research and patient-led activities.

In the words of EURORDIS President Terkel Andersen: "The adoption of the Council Recommendation on European Action in the field of Rare Diseases is one of the most important EU decisions in the domain of public health so far. A coordinated European Action for Rare Diseases is not only logical and meaningful in terms of using available resources in the best way, but will have enormous impact on quality of life and survival for millions of patients all over Europe.

In the future we expect delay to diagnosis to be reduced and access to expert treatment to be significantly improved. Strengthened collaboration between Member States will raise hopes that new treatments will be made available for hundreds of diseases which at this point are the true orphans of our health care systems. The comprehensive approach used in the Recommendation reflects that now it is fully recognised that involvement of patient organisations is essential to develop efficient national strategies and reach best standards of care."

Now that the policy instruments are in place EURORDIS, together with all other interested parties, will follow-up on the implementation of the Council Recommendation at the European and national level.

For more information:

[Eurordis' past article on the Commission Communication and proposed Council Recommendation](#)

[Eurordis' past article on the EuroPlan Project to promote National Plans for Rare Diseases](#)

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### About EURORDIS

The European Organisation for Rare Diseases (EURORDIS) represents more than 350 rare disease organisations in 39 different countries, covering more than 1,000 rare diseases. It is therefore the voice of the 30 million patients affected by rare diseases throughout Europe.

EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe. It is supported by its members and by the French Muscular Dystrophy Association (AFM), the European Commission, and corporate foundations and the health industry. EURORDIS was founded in 1997. Further details concerning EURORDIS and rare diseases are available at: <http://www.eurordis.org>