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Project co-financed by:
EU Public Health
Programme 2008-2013



Financial support:

CSL Behring



Sigma Tau



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**European policy on rare disease gathers momentum at the
European Conference on Rare Diseases - ECRD 2010 Krakow**

PRESS RELEASE – May 19, 2010. An unprecedented number of participants attended the largest ever European Conference on Rare Diseases (ECRD), which was held in Krakow, Poland this weekend (May 14 & 15, 2010).

Over 600 participants from 43 countries, a third of which came from Eastern Europe, gathered to discuss key policies and actions to improve the lives of those affected by these conditions.

Dr Andrzej Ryś, Director for Public Health at the European Commission, opened the Conference by declaring that the overall number of patients suffering from rare diseases, the high European added value due to the rarity of patients and experts for each rare disease together with the limited access to information, to treatment opportunities and drugs available, constitute a challenge that justifies action from the European Union in this field. He highlighted that Member States have until 2013 to adopt rare disease plans or strategies in their own countries based on common policy recommendations.

According to Director of Orphanet, Dr Ségolène Aymé's presentation, National Plans have already been adopted in France, Portugal, Greece, Bulgaria and Spain, and are well under way in Germany, Romania and the UK. The first steps have been taken in other countries, such as Poland, host to the Conference.

"This ECRD 2010 Krakow has served to identify those areas that need better policies in order to fulfil the objectives of the [Council Recommendation](#) and to build momentum for national plans and strategies to be implemented across Europe," declared Yann Le Cam, CEO of the European Organisation for Rare Diseases (EURORDIS).

"Indeed, the momentum applies to Poland as 20 Polish patient representatives, health-care professionals and scientists met on the first day of the Conference to sign a Common Declaration to the government calling to establish a National Plan for Rare Diseases in Poland. They also suggested following the EuroPlan guidelines to accomplish their goals."

Measures to improve accurate diagnosis and early treatment of many rare diseases were presented at the Conference, namely:

- Coding and classifying rare diseases and integrating them in the WHO's International Classification of Diseases system.
- Identification and support of centres of expertise in all European countries and pooling existing expertise through European Reference Networks.
- Sharing research infrastructures (databases, biobanks and registries), involving patient organisations in clinical trials
- Making the best use of knowledge and funds for genetic testing.

The ECRD 2010 Krakow was also the occasion to present the EU Committee of Experts on Rare Diseases. The Committee, which will include around 50 representatives of all stakeholder groups, will act as a sort of 'Parliament' of the rare disease community in order to follow-up on the work initiated at the biennial Conference.

The ECRD series is a unique forum that sees patient representatives of all the rare diseases, from the majority of European countries and further afield, gather with health-care professionals, academics, researchers, policy makers and industry representatives to discuss the most recent rare disease initiatives in the fields of research, health-care, information and social services.

ECRD 2010 Krakow is organised by The European Organisation for Rare Diseases (EURORDIS) in partnership with Rare Disorders Denmark, the National Health



EURORDIS
Rare Diseases Europe

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Institute (UK) and the Fundació Doctor Robert, Autonomous University of Barcelona. It is primarily supported by the Public Health Programme of the European Commission, co-funded by CSL Behring, Novartis and Sigma Tau, with additional sponsorship from 10 other companies.

For more information (presentations and photos) visit: www.eurordis.org and www.rare-diseases.eu

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Rare Diseases

A rare disease is considered as that when it affects less than one in 2000 people. Rare diseases are chronic, progressive, degenerative, and of the life-threatening. There is no cure today for the 6000 – 8000 rare diseases identified, of which 75% affect children. Due to their rareness information is scarce and research is insufficient. People affected by rare diseases face common challenges such as diagnosis delay, misdiagnosis, psychological burden and lack of practical support for everyday life. About 30 million people suffer from a rare disease in Europe today.

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About EURORDIS

The European Organisation for Rare Diseases (EURORDIS) represents more than 400 rare disease organisations in 43 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. More information on: www.eurordis.org

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