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European Conference on Rare Diseases

Krakow 2010

PRESS RELEASE – May 14, 2010. Today begins the 5th European Conference on Rare Diseases 2010 Krakow (ECRD 2010 Krakow). More than 600 participants from 43 countries are attending the event. During the Conference, the European Commission will unveil the road map for the implementation of the European action in the field of rare diseases.

A year after the adoption of the [Commission Communication on Rare Diseases](#) and of the [Council Recommendation for Action in the field of Rare Diseases](#), ECRD 2010 will be the opportunity to highlight success, measure the progress to date and assess the main challenges for next years. "ECRD 2007 Lisbon was about shaping policy. ECRD 2010 is about implementing that policy," says Yann Le Cam, CEO of EURORDIS. "Throughout the Conference we will be highlighting successful measures in order to share best practice. We will also pinpoint those areas where better policies are needed to fulfil the objectives Member States committed to when they adopted the Council Recommendation in June 2009."

Collaborating
partners:

Dutch Steering
Committee on Orphan
Drugs and Rare
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This year, the event entitled, "From Policies to Effective Services for Patients", will present the most recent rare disease initiatives in the fields of research, health care, information and social services. Hot topics such as access to genetic testing and to cross-border health care in an enlarged Europe will be debated. Overall, there will be 24 different sessions covering 8 themes, involving about 100 speakers and chairpersons and interpreted in 2 to 5 languages (English, Polish, German, Spanish and French).

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Prestigious personalities such as: Mr Marek Twardowski, Undersecretary of State, Ministry of Health Poland, Dr Andrzej Ryś, Director of Public Health, European Commission, Prof Hans Georg Eichler, Senior Medical Officer, European Medicines Agency and Mr Terkel Andersen, President of EURORDIS and of the Danish Haemophilia Society, will present at the Conference.

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CSL Behring



Sigma Tau



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The responsibility of the content and programme of the Polka project lies with the project partners. The Executive Agency is not responsible for any use that may be made of the information contained therein.

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To see the Programme and for more information, visit: 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.

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