



RARE DISEASE | UK

The National Alliance for people with rare diseases & all who support them

News Release

Immediate Release 10th June 2009

Patients, clinicians and industry welcome EU Health Ministers' move to tackle rare diseases

Rare Disease UK, the national alliance of patient charities, medical professionals and industry representatives, has welcomed the adoption yesterday by EU Health Ministers of a Council Recommendation that calls on Member States to develop and implement plans or strategies for the treatment of rare diseases.

Alastair Kent, Chair of Rare Disease UK, said: "This is an important step forward for the estimated 3.5 million people in the UK who are affected by rare disease, We are also delighted that this initiative has received wide cross-party support. It now needs to be taken forward in all the nations of the UK."

He added: "It is important that families affected by rare conditions are offered a strategic approach to the provision of their healthcare. We are still hearing frequently that patients are having difficulties accessing high quality care and services. A national strategy for integrated service delivery would help to ensure that these vital services reach all the people who so desperately need them."

Dr Peter Corry, a leading Paediatrician at St Luke's Hospital, Bradford, said: "Diagnosing rare diseases, many of which are severe or life-threatening, is often difficult and the complex treatments required may involve several specialists. A national strategy that integrated rare disease services would enable patients and health professionals to provide and use best practice care and the health services to make best use of scarce expertise and improve outcomes for patients."

There are over 6000 rare conditions identified, and they affect over 3.5 million people in the UK and over 30 million people in the EU at some point in their life.

– Ends –



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Note to Editors:

1. For case studies of patients and interview requests please contact Melissa Hillier at Rare Disease UK on 020 7704 3141, 07827 871737 or melissa@raredisease.org.uk .
2. Rare Disease UK is a joint initiative of the [Genetic Interest Group](#), (the UK alliance of patient organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders) and others in response to unmet health care needs of families who currently struggle to get access to integrated care and support from the NHS.
3. The EU's Council of Ministers consists of representatives of Member States at ministerial level. In this case, the Member States' Health Ministers (collectively known as the Health Council) have adopted the Council Recommendation on a European action in the field of Rare Diseases.
4. 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** 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
5. Further information and reports will appear on the Rare Disease website: www.raredisease.org.uk
Rare Disease UK is registered at Unit 4D, Leroy House, 436 Essex Road, London N1 3QP.