



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

news release

Immediate Release: 11th November 2008.

European Commission announces strategy to help 3.5 million patients in the UK

Rare Disease UK welcomes the European Commission's Communication which was adopted today and sets out an EU wide strategy to help support Member States in diagnosing, treating and caring for the 36 million EU patients with rare diseases. Over 3.5 million patients in the UK are affected by a rare disease at some point in their life and services for these many million need to be improved, and coordinated.

Alastair Kent, Director of the Genetic Interest Group a founder organisation of Rare Disease UK commented, *"This is a landmark development for the profile of rare diseases in Europe, the UK and member countries. We look forward to working with Rare Disease UK and their stakeholders from research, the patient community, industry, the health service and government to deliver meaningful change"*.

The Communication outlines a strategy for action in three main areas on rare diseases:

1. improving recognition and visibility of rare diseases

Rare Disease UK sees this as an opportunity to improve the often difficult first step on the right path to good clinical care and knowledge.

2. supporting national plans for rare diseases in Member States

Rare Disease UK hopes this will bring together often disparate communities in rare disease care, thereby fostering improved communication and care for patients.

3. Strengthening cooperation and coordination for rare diseases at European level.

Rare Disease UK believes that by bringing specialist expertise from across Europe together to benefit all citizens, duplication in research will be minimised, and progress towards cures and or treatments will be accelerated.



- Ends -

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For more information and to join Rare Disease UK please contact

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Editors Notes:

- Rare Disease UK launched in November 2008
- 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.
- 1 in 17 people will develop a rare condition at some point during their life.
- There are over 30 million people living in the European Union affected by a rare disease and 3.5 million in the UK.
- The European Commission adopted the Communication on a European Action in the Field of Rare Diseases on 11th November .
<http://europa.eu/rapid/pressReleasesAction.do?reference=IP/08/1681&format=HTML&aged=0&language=EN&guiLanguage=en>
- European Conference on National Strategies and Plans for Rare Diseases in Europe.
http://ue2008.fr/PFUE/lang/en/accueil/PFUE-11_2008/PFUE-18.11.2008/strategies_et_plans_nationaux_pour_les_maladies_rares_en_europe
- European Commission website on Rare Diseases
http://ec.europa.eu/health/ph_threats/non_com/rare_diseases_en.htm
- Further information and reports will appear on the Rare Disease website shortly please do bookmark the page www.raredisease.org.uk

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