



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

news release

Immediate Release: 6th November 2008.

Rare Disease the unseen Public Health Challenge

[Rare Disease UK](#) launched today, a UK alliance of patients, doctors, specialist researchers, health care planners, politicians and industry in pursuit of the shared goal of high quality healthcare for patients and families living with rare disease.

For patients, families and individuals affected by rare diseases getting access to services can be difficult. Finding expert help is too often a matter of chance rather than a consequence of systematic planning by the NHS. Paradoxically although any given rare condition may only affect a few families across the UK because there are so many different diseases many hundreds of thousands of families struggle to get the services they need. With over 6000 rare diseases identified they will affect over 3.5million people in the UK at some point during their lifetime¹

Rare Disease UK will campaign for the adoption and implementation of National Plans in each of the UK's home nations. These plans should ensure provision of integrated services tailored to the specific needs of those with rare conditions, they will help make best use of NHS resources and ensure that scarce clinical expertise is deployed to best advantage for patient benefit.

- Ends -

¹ Extrapolated from Rare Disease Day website www.rarediseaseday.org



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For more information and to join Rare Disease UK please contact

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- Rare Disease UK launched on 6th 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.
- Public Consultation regarding a European Action in the Field of Rare Diseases The European Commission plans to publish in November 2008 a Communication on a European Action in the Field of Rare Diseases. This communication will be the culmination of a process starting with the current consultation aiming at gathering expertise in all Member States.
http://ec.europa.eu/health/ph_threats/non_com/cons_rare_dis_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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