



RARE DISEASE | UK

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

News Release

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NHS plan for rare diseases must be a priority for government Campaign group launched on Rare Disease Day 2009

A coalition of patient charities, medical professionals and industry representatives have called on Department of Health Ministers to move forward with EU proposals to develop a national plan for the treatment of rare diseases.

Rare Disease UK is formally launched today on Rare Disease Day 2009 in the House of Commons.

Alastair Kent, Chair of Rare Disease UK, said: "It is a national disgrace that the NHS does not have a coordinated plan to treat the many thousands of people who are every year affected by rare diseases. Currently patients, families and individuals affected by rare diseases are denied their right to high quality care and support, due to a lack of coordination and information provision to both health professionals and patients. Finding expert help is too often a matter of chance rather than planning by the NHS. A national plan would help to bring together expertise and skill to ensure that patients with rare conditions are not denied high quality care".

He added: "The paradox of rare diseases is that they collectively affect over 3.5 million people in the UK but that all too often patients go undiagnosed and misdiagnosed with appalling consequences. Ministers can do more and must do more to make the NHS fit for the purpose of treating rare conditions."

Dr Peter Corry, a leading Paediatrician at St Luke's Hospital, Bradford, said: "Many rare diseases are severe, or even life-threatening. Diagnosis is often difficult and the complex treatments required may involve several specialists. Frontline medical staff need good sources of up-to-date information, clear pathways and access to the appropriate experts."

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.

A European survey of patients with rare diseases published today shows:

- 40% of respondents to a recent survey of patients said they received the incorrect diagnosis
- 25% of patients waited between 5 – 30 years for a correct diagnosis.

- 50% of respondents seeking social services reported that their expectations were only met “somewhat” or even “not at all”

The report can be downloaded at the following URL: http://www.eurordis.org/article.php3?id_article=1912

- Ends –

Note to Editors:

1. For case studies of patients and interview requests please contact Rare Disease UK on 020 7704 3141. 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. Rare Disease Day is being marked on 28th February. It is an international day to raise awareness of rare conditions www.rarediseaseday.org
4. 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.
5. The European Council of Ministers is expected to ratify a European Commission communication later this year requiring all Member States to develop national plans for the treatment of rare diseases.
6. 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.