



RARE DISEASE | UK

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

News Release

Immediate Release 26th February 2009

Patients, clinicians and industry call for high quality integrated care to be given to all patients with rare conditions.

A coalition of patient charities, medical professionals and industry representatives met at the House of Commons yesterday to call on the Department of Health Ministers to move forward with EU proposals to develop a national plan for the treatment of all rare diseases.

Alastair Kent, Chair of Rare Disease UK, said: "It is important that those affected by rare conditions are offered a strategic approach to the provision of their healthcare, currently it is all too frequent that patients with rare conditions are left without accurate information and unable to find adequate support. The development of a national plan will go a long way to providing the best practice care and support that the estimated 3.5 million patients with rare conditions desperately need".

He added, "Having an international day to raise awareness of Rare Diseases helps to bring this issue to the forefront of people's minds. Rare Disease Day highlights that patient care is a public affair and one that will not resolve itself without input from Government".

Dr Peter Corry, a leading Paediatrician at St Luke's Hospital, Bradford, a keynote speaker at the Rare Disease Day reception said: "I have come here today with colleagues and patients from Bradford as we all feel strongly that raising awareness of rare conditions is vital to improving the lives of those living with severe, or even life-threatening conditions. 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. The Payment by Results system of payments for hospital clinics often doesn't reflect the complexity of these rare, and often complex conditions"

Kerry Leeson, from Alstrom Syndrome UK spoke about the benefits of having coordinated care, "As a parent of a child with Alstrom Syndrome, I feel very fortunate to have access to specialised multi-disciplinary clinics. The clinics make such a difference to our lives and it makes us feel increasingly confident that the specialists we see are fully aware of the condition and the problems many of our families face".

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.

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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.