



*Working to benefit all people
affected by genetic disorders*

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news release

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**A Rare Day for Rare Disease
29th Feb is celebrated as First European Rare Disease Day
with UK reception in the House of Commons**

To mark Europe's first Rare Disease Day 29th February 2008 over 150 patients from across the country travelled to Westminster to meet parliamentarians face to face to raise the awareness of the needs of patients with rare diseases and to discuss policy developments at a UK and European level.

The event in the House of Commons was organised by Genetic Interest Group (GIG), a national alliance of patient organisations which support children, families and individuals affected by genetic disorders in the UK, and their European partner Eurordis (an alliance of patient organisations and individuals active in the field of rare diseases).

Policy developments discussed included GIG's pivotal input into upcoming European initiatives to ensure equal access and availability of prevention, diagnosis, treatment and rehabilitation for people with Rare Disease and how the UK experience could provide a role model in some areas.

Although the UK does have specialist commissioning for some rare diseases it is not accessible by all and patients with rare conditions are calling for equal access to these health services. Tanya Collin-Histed, Executive Director at the Gauchers Association, a disease that affects 245 people in the UK, spoke about the benefits some patients had gained through receiving treatment and care at these specialist centres, "Being able to see specialists in a centre dedicated to our condition has been of enormous benefit to patients. They are able to see people who look at their condition as a whole, and who know about the effects that it can

have. They also have access to the latest treatment developments. It has been a lifeline to patients.”

Alastair Kent, Director of the GIG said, “Raising awareness of genetic disorders is vital. Although alone they are rare, together there are over 3.5 million people in the UK affected. Many patients have similar issues and concerns and together we can help patients to access the NHS in a fair and equitable manner”.

Also discussed were

- The importance and need of funded research and care in the rare disease area
- The need for specific health policies, support networks, best practice guidelines, and increased expertise among carers and healthcare professionals in the UK of rare diseases.
- The need to ensure common policy guidelines are developed and shared everywhere in Europe: specific actions – in areas such as research, centres of expertise, access to information, incentives for the development of orphan drugs, screening

Rare diseases are life-threatening or chronically debilitating diseases with a low prevalence and a high level of complexity. There are over 8000 rare conditions identified, and they affect over 3.5 million people in the UK and over 300 million people in the EU at some point in their life.¹ Patients with very rare diseases, and their families, are particularly isolated and vulnerable and a day focussed on rare diseases can bring hope, as well as information to these individuals.

The London Parliamentary reception which took place on Tuesday 26th February to highlight the impact of rare conditions was just one of many events taking place throughout Europe to mark the day.

Rare Disease Day will happen every year from 2008 onward and will continue to drive the understanding of genetic disorders and the impact that they have on patients’ lives among the media, decisions makers, health professionals and the general public.

- Ends -

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

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Notes to Editors

- The Genetic Interest Group (GIG) is a UK national alliance of organisations with a membership of over 130 charities that support children, families and individuals affected by genetic disorders.
- GIG's primary goal is to promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them.
- Rare Disease Day is a European Event co-ordinated by the European Organisation for Rare Diseases – Eurordis www.eurordis.org and is on 29th February. Events will take place across Europe for more information www.rarediseaseday.org
- There are over 8000 identified rare diseases
- 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.
- A European Parliament Rare Disease Communication was published in November 2007 and this document discusses the possibilities for improving healthcare for patients with rare diseases in Europe by sharing information and knowledge between experts and between countries. For more information

http://ec.europa.eu/health/ph_threats/non_com/cons_rare_dis_en.htm

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