



*Making life better for people
affected by genetic disorders*

Unit 4D Leroy House
436 Essex Road
London
N1 3QP
Tel: 020 7704 3141

news release

Immediate Release: 10th June 2009

The Genetic Interest Group welcomes EU Health Ministers' move to tackle rare diseases

The Genetic Interest Group, the UK patient organisation for all those affected by genetic disorders, has welcomed the adoption yesterday by EU Health Ministers of a Council Recommendation that calls on Member States to develop and implement plans or strategies for the treatment of rare diseases.

Alastair Kent, Director of the Genetic Interest Group, said: "This is an important step forward for the estimated 3.5 million people in the UK who are affected by rare disease. We are also delighted that this initiative has received wide cross-party support. It now needs to be taken forward in all the nations of the UK."

He added: "It is important that families affected by rare conditions are offered a strategic approach to the provision of their healthcare. We are still hearing frequently that patients are having difficulties accessing high quality care and services. A national strategy for integrated service delivery would help to ensure that these vital services reach all the people who so desperately need them."

Dr Peter Corry, a leading Paediatrician at St Luke's Hospital, Bradford, said: "Diagnosing rare diseases, many of which are severe or life-threatening, is often difficult and the complex treatments required may involve several specialists. A national strategy that integrated rare disease services would enable patients and health professionals to provide and use best practice care and the health services to make best use of scarce expertise and improve outcomes for patients."

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.

– Ends –

For more information please contact

Alastair Kent, Director - Genetic Interest Group 07740 931646

Email address alastair@gig.org.uk

Melissa Hillier, Assistant Director - Genetic Interest Group 07827 871737

Email address: melissa@gig.org.uk

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.
- Individually, many genetic conditions are rare and as such it is difficult to raise their profile and the needs of those affected by them. GIG provides a common platform from which effective programmes to raise awareness, inform the media and influence government, industry and the NHS can be launched
- As an organisation focusing on issues of policy and practice GIG keeps an active watch on developments in the UK and Europe that will influence the effective transfer of knowledge and understanding into products and services for families that are supported by our member groups.
- In a potentially controversial field like genetics GIG provides a strong voice advocating the benefits of scientific progress in understanding the contribution being made now and that will be made in the years to come for improving health and combating many currently incurable diseases.
- For more information please go to www.gig.org.uk
- The Genetic Interest Group has jointly founded [Rare Disease UK](#) with others in response to unmet health care needs of families who currently struggle to get access to integrated care and support from the NHS.
- The EU's Council of Ministers consists of representatives of Member States at ministerial level. In this case, the Member States' Health Ministers (collectively known as the Health Council) have adopted the Council Recommendation on a European action in the field of Rare Diseases.
- The Council Recommendation is important because it calls for concerted action at EU and national level in order to:
 - Ensure that rare diseases are adequately **coded and classified**
 - Enhance **research** in the field of rare diseases
 - Identify **Centres of Expertise** and foster their participation into **European Reference Networks**
 - Support the **pooling of expertise** at European level
 - Share assessments on the clinical added value of **orphan drugs**
 - Foster **patient empowerment** by involving patients and their representatives at all stages of the decision-making process
 - Ensure the **sustainability** of infrastructures developed for rare diseases

Registered Office:

The Genetic Interest Group
Unit 4D, Leroy House
London
N1 3QP

A Registered Charity (Number 1114195)

A company Limited by Guarantee (Number 05772999)