



*Working to benefit all people
affected by genetic disorders*

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News release

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Patient organisations at the heart of the debate on effective regulation in medical research and genetics

Human Rights, Privacy and Medical Research, a new report written by John Gillott, was launched this week by the Genetic Interest Group. This report traces the impact that the right to privacy is having on medical research and clinical practice, with a particular focus on human genetics.

In the last five years since the implementation of the Human Rights Act and the Data Protection Act the situation for researchers, who in the past were encouraged to use health data in the public interest without always seeking consent, has changed beyond recognition. This report highlights the new issues and debates that researchers are now facing in the current research climate and discusses how this will have an impact on patients living with genetic disorders who will be the eventual beneficiaries of this research.

At the launch of the report in the House of Commons, Alastair Kent, Director of the Genetic Interest Group, commented, "This report and the debates we have had looking at these issues highlight that patients are keen for researchers to use their samples effectively and with the appropriate regulation. What patients don't want to see is over burdensome regulation that hinders progress in finding treatments and therapies for their conditions"

Copies of this report can be downloaded free of charge at www.gig.org.uk/latest-news.htm or a hard copy can be requested from the GIG office for £7.50 including p&p.

Ends

For more information, please contact:

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Notes to Editors

- **The Genetic Interest Group (GIG)** is a national alliance of organisations with a membership of over 130 charities that support children, families and individuals affected by genetic disorders.
- It'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.

Registered Office:

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A Registered Charity (Number 803424)