



***Working to benefit all people
affected by genetic disorders***

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news release

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UK's first website for genetic disorders launched

The UK's first website to offer comprehensive information on genetic disorders is launched today 10th December 2002 by The Genetic Interest Group (GIG), a registered charity and national alliance of patient organisations. The site, at www.gig.org.uk. Is the first comprehensive website to provide a unique source of information for a range of people, from patients and families right through to policy makers, health care professionals and teachers. It contains all the latest policy documents that GIG have produced, as well as information on all our member groups, including website links.

There are also interactive features with video testimonies by GIG members who are the families, children and individuals affected by genetic disorders. The testimonies provide an insight into what it is like to live with a genetic disorder and encourage people to participate in the online survey about each clip they view.

Alastair Kent, Director of the Genetic Interest Group said: "The website provides the opportunity for those who live with genetic disorders every day to have a say on the issues that really matter to them". Ann Hunt MBE, Head of Research at the Tuberous Sclerosis Association, a member of GIG, commented: "The site is bursting with useful links and information." The personal experiences are very interesting and will remind all the worthy people and organisations who discuss 'genetic' topics of the reality behind the issues.

Vicky Cowell, who is a cystic fibrosis parent and member of GIG said: "I was delighted to be given the opportunity to talk about what it is really like living with someone with CF in the family, and what our hopes are for the future. I hope our small contribution helps patients and family members visiting the website, who may need a bit of positive reassurance from people in the same situation as themselves."

The Genetic Interest Group was established in 1989 and aims to promote an awareness and understanding of genetic disorders to the public and also to government and industry. GIG is a voluntarily funded organisation which works tirelessly in providing a voice for patients and families with genetic disorders through policy papers, lectures, seminars and debate..

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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 120 charities that support children, families and individuals affected by genetic disorders.
- Our 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)