



History of Genetic Alliance UK (Formerly known as Genetic Interest Group [GIG])

**This report was written in 2006 when the organisation was
known as Genetic Interest Group.**

**We are looking to update the branding of this document in the
near future.**

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The Genetic Interest Group today

Today, as it enters its 17th year, the Genetic Interest Group is a reputable charity dealing with current issues of clinical genetics and representing 140 patient groups..

Many of its members are smaller voluntary organisations focused on the immediate needs of their members and their specific condition. GIG enables such groups to stay in touch with broad genetic policy which, while it certainly affects them, they may lack the resources to keep up with. Through consulting with its members, GIG coordinates patient interests with its policy and project research, with the aim of improving patient services. The organisation's work ranges from keeping in touch with members to taking part in international projects in Europe and beyond.

Giving patients a voice

In the UK GIG has made significant strides to give patients a voice. This has led to better genetic services in the National Health Service (NHS).

For example:

- GIG has influenced UK policy on genetic research. In 2003 - 2004 GIG lobbied to amend the Human Tissue Bill, which subsequently became the **Human Tissue Act (2004)**, to ensure that research for patients living with a genetic disorder was not hampered.
- GIG representatives sit on the Department of Health's key genetic committees – **Genetic Services Commissioning Advisory Group (GenCAG)** and the [United Kingdom Genetic Testing Network \(UKGTN\)](#) – where they represent GIG members' viewpoint on policies for NHS genetic services.
- Other recent work includes GIG's [Family Route Map](#) project, which will help patients and their families get access to services and information currently available.

Additionally, in the 12 months up to August 2006, visits to GIG's website doubled, showing clearly how much the organisation's information is valued.

Equal access and high standards

An important aim for GIG is to try to ensure that patients and patient families all have equal access to quality health services and accurate information about genetic services. GIG is involved in many projects with this aim, notably the London IDEAS Translation Project (see below) and also the Beacon Project, which is designed to implement ethnic monitoring in the UK's regional genetic



centres. Both of these stem from the 2001 Ethnic Monitoring in Clinical Genetics project, which pinpointed inequalities and has prompted a wide range of collaborative initiatives to tackle the shortcomings which were discovered.

In Europe, GIG is involved in a number of ways. It contributes to EuroGentest, which aims to give all EU citizens equal access to high-quality services. It has also helped with involvement in [Orphan Medicinal Product Regulation](#) to encourage drug companies to provide medicines for the rarer disorders, where there is not an obviously commercially viable market.

GIG's growing staff demonstrates the organisation's success and its ongoing efforts to respond to member groups' needs. Since 2003 there have been new staff additions, which include fundraiser, project officer, project implementation officer, and an expansion of work on policy issues. GIG is currently looking for a fundraiser. As well as taking on more staff in London, regional staff have been added; Gillian Scott in Scotland and Buddug Williams in Wales respond to the genetic needs of patients in these areas. Having more staff makes it possible to improve communications, get involved in more projects, and provide better services for GIG's members.

As genetics moves into mainstream medicine GIG has become a strategic organisation which seeks a common policy among its members in order to present an influential voice for the patient in medical science and health care.

What everyone wants, no matter what the genetic disease or disorder they have, is to feel that if something can be done it will be done, that it will be done in a way that reflects the best possible understanding of what the condition and implications are, it will incorporate the best possible clinical practice...and it will be done in a way that is timely, that is user friendly, that is appropriate, that is targeted.

Alastair Kent,

Director of GIG.

Roots of GIG

In the late 1980s there were a large number of policy issues developing in genetics including the beginnings of the debate on the use of genetic test results in insurance and employment contexts, discussions of Intellectual property and patenting and the uses of data derived from samples gathered from indigenous groups in the developing world. In the NHS regional genetic centres were expanding and there was discussion of resources and staffing levels, whilst the Warnock Committee's report led to the introduction of the Human Fertilisation



and Embryology Bill (and indirectly to GIG) in 1989. There were many patient support groups, but little communication between them and most, entirely run by volunteers, could only handle the immediate concerns of their members' disorder and carried out no policy work. Before the Genetic Interest Group (GIG) there was no single body that could even begin to represent patients with genetic disorders whether that was to government bodies, health organisations, or pharmaceutical companies.

People broadly agreed that paying attention to policies would lead to improvements in services to patients and most people could see that science was on the brink of a genetics revolution

The idea of Genetic Interest Group (GIG) began in May 1987. Shirley Dalby of the [Huntington's Association](#) (then Huntington's Chorea) invited seven similar voluntary groups to discuss the idea of an alliance for people affected by genetic disorders. The rarity of many disorders limited the ability to lobby for better health services; an alliance might share information and bring issues into the public eye that affected many faced with a genetic disorder. It might improve the opportunities for research and development, along with the treatment and care of patients. An umbrella organisation could channel pressure for better services, act as a contact between groups, provide the public and its members with



information and education about genetic disorders, and most of all, create one recognised voice instead of many smaller ones.

GIG pursues the common interests of a wide range of groups. It was never intended that it would replace the service of its members.

The needs of people with specific genetic disorders were better served by the separate groups who would continue to raise funds for their own conditions.

Ann Hunt

Chair of GIG, 1989–1994

GIG Today September 1989.

In 1988 the groups made a proposal to the [Clinical Genetics Society](#) meeting in Oxford. Ann Hunt – at that time chairwoman of the [Tuberous Sclerosis Association](#) – and Christine Lavery, Chief Executive from the [Mucopolysaccharide Diseases \(MPS\) Society](#) set out their ideas to the professional clinicians

The conference responded very positively to the idea. People could see that it would be good for patients as well as for doctors and researchers. The medical community, including that of clinical genetics, recognised the importance of the

patient view in influencing the policy agenda. People recognised that the new group could act as a point of contact for professionals, to help them locate specific support groups and help their patients. Amid the reorganisation of the NHS into a system of purchasers and providers, which was going on at the time, there was concern that patients' needs might get lost in the shuffle. Fortunately Ann Hunt chaired the Oxfordshire Community Health Council and thus knew about these new processes and could help fit GIG, the voice of the patient, into the changes.

GIG takes shape

It's one thing to have an aspiration, another to be able to do something with that.

John Dart

Director, [DEBRA](#) and Trustee of GIG

GIG was inaugurated on 22 April 1989 with the backing of 60 groups. The organisation began with no employed administrative staff and Ann Hunt chaired it herself to ensure that the vision was followed through into reality.

Whatever you say about the history of GIG, Ann Hunt has to take 110 per cent of the credit for making something happen. For sticking at it and going for it.



Joanie Dimavicius, former Director of Ante Natal Results and Choices

The first management council held its meetings at St. Mary's Hospital, London. GIG's main aim then, as now, was to improve services for those living with genetic disorders as well as to raise public awareness about genetic conditions. The strength of GIG comes from its members, who endorse its role as their representative, enabling it more powerfully to deliver its message. Ann Hunt's hope was for GIG to become 'an extended family of people working for better services for everyone affected by a genetic disorder' (*GIG Today* September 1990). Each founding group and those that joined later were able to share their varied skills and knowledge among a wider audience and this in turn has helped to strengthen both GIG and those it represents.

GIG quickly began to make an impact with health professionals, politicians, and policy-makers among others. It was clear that there was a need for the perspective of the patient to be taken account of in this area of medicine. Some pressure was needed to create momentum from scientific discovery to practical health services in an acceptable time for patients. At this time there were debates going on among academics, medical professionals and the media about complicated issues, such as research using embryos and the ethics of genetic engineering. No one was specifically informing patients and patients' families



about these discussions or asking for their views. GIG board members included genetic experts and medical advisers who helped the charity to lead on the education of politicians, clinicians, and the public on all implications of genetics. This helped GIG establish itself as a credible and valuable organisation in the eyes of decision-makers and politicians.

Pharmaceutical companies and insurance firms also saw the benefit of having a single body with which they could communicate, confident that this body was an accurate and representative embodiment of the views of patients with genetic disorders.

Early days

GIG, like many charities starting up, ran on the goodwill and generosity of the founding members. A logo was designed – for free – and GIG was delighted when a printing firm donated 8,000 sheets of headed paper. [Contact a Family](#) provided GIG's small secretarial needs, and the first four issues of *GIG Today* were printed by the [Cystic Fibrosis Trust](#).

From the outset in 1989 GIG was in communication with the heads of the relevant departments at the Department of Health and Social Security, (now the



Department of Health), who were pleased to have, `a single channel of communication in consulting with the voluntary sector on these [genetic] issues.’¹

Charity status was granted in June 1990. GIG appointed an honorary treasurer, John Gluckstein, who remained in this role until June 2005 when he retired. John was working as a trustee for one of GIG’s member groups at the time and was only too pleased to be able to help out. Having worked in business for many years, John felt he could contribute by looking after the accounts of this new and exciting organisation.

I didn't know anything about genetics but I knew that I could help with the finance side of things. I have to say that they couldn't pass me the account books quick enough!

John Gluckstein

Honorary Treasurer of GIG, 1989–2005

Legislative advocacy

The Human Fertilisation and Embryology Bill consultation. was GIG’s first major lobby for legislative change.

¹ Letter to Ann Hunt from J C Reed, Department of Health and Social Security 13 September 1989

It was a bitterly cold day when GIG lobbied Parliament in December 1989. Many parents had brought their disabled children with them. We were allowed to give a continuous session of experiences of genetic disorders from inside Westminster Hall, with MPs coming down to see their constituents there.

Ann Hunt

Chair of GIG, 1989–1994

On the day the Bill was transferred from the House of Lords every member of the House of Commons received the GIG statement. GIG was also mentioned several times during the Second Reading in the House of Commons debate in April 1990. GIG successfully coordinated the views of patients with genetic disorders and ensured that its members worked together. This was one of the first actions which brought GIG into existence as a policy organisation.

With the work that was carried out in this campaign GIG was able to produce the first in a series of small factsheets, ***Lobbying your MP – a short guide.***

Publications such as this served all member groups and gave patients who were struggling to find a voice a starting point from which to lobby for their MP's attention. GIG also held workshops for patients on counselling, prenatal

diagnosis, and support after termination. Financially this was feasible with an annual income of just £740.66.

Public awareness

There was a continuous effort to educate policy and law-makers as well as accurately to represent the views of patients view and to promote their rights.

We felt it important in this controversial field to have access to the impartial advice of such a charity. The task of informing Parliamentarians about genetics is supremely important and at the same time challenging.

Viscount Craigavon, Secretary, **All-Party Parliamentary Group on Human Genetics,**

GIG Annual Report 1997 - 1998

GIG surveyed the services offered by NHS genetic counselling centres as members felt it was important to establish how these services were to be financed in the reorganisation of NHS services.

The survey findings were presented to the Department of Health, highlighting many of the difficulties that GIG's members had in accessing genetic services.

This was welcomed by the Department of Health and the information was taken

into consideration when its review of services was completed. GIG also undertook the important task of interpreting government policy and science documents and explaining to members how all this related to the fundamental issues that most concern patients with genetic disorders.

Interface meetings and workshops

From the outset GIG organised and ran meetings in which professionals and patients could discuss issues, such as transition of services (from childhood to adult), employment and insurance, and how to collect research data for your members (useful for researchers as well as patients). It called these interface meetings; half the participants are professional, half are patients. This encourages communication on an equal level.

The meetings were like debates, so that all were encouraged to speak and to produce a policy of intent, a way to take the issues forward. Meetings and multidisciplinary workshops to facilitate debate and input into policy are still a large part of GIG's work. GIG not only organises workshops to help frame its policies, it also holds workshops in which patients can feed into policy development and research at a national level.

Towards a distinct identity



Even in its early years GIG worked in Europe – though its main focus remained England and the UK. Towards the end of 1991, GIG joined with other umbrella organisations in Europe and was involved in a project to provide educational materials for secondary schools on the wider aspects of human genetics and the responsibility of every person to know their genetic status.

At this time GIG was depending on the tremendous hard work from all the management committee, whose members donated spare time and energy. With funding from The Wellcome Trust, GIG produced and distributed 13,000 posters and 30,000 leaflets to GP surgeries and paediatricians throughout the UK. During 1991 GIG responded to the *Clothier Committee on Gene Therapy*, the Department of Health consultation document *Health of the Nation* and began to speak to the media about genetic issues.

In 1992, with the help of a small grant GIG was able to employ a part-time secretary, Patricia van Aardt, who was based at the Institute of Molecular Medicine in Oxford. As chairwoman, Ann Hunt continued to work on a voluntary basis from her spare bedroom just outside Oxford.

GIG gained a respected base at the Institute of Molecular Medicine in Oxford, which not only helped alleviate the burden of work that the chairwoman



undertook, but also gave an official address for correspondence. GIG became more visible.

When GIG was formed in 1989 it was a umbrella group of very dissimilar organisations, ranging from large business-like charities to small self-help groups representing only a few families. Each of the organisations had their own agenda, their own reason for seeing GIG as a forum for publicising the needs of their particular group. This year however, I have felt for the first time that members now see themselves as a wider community of people, whose lives have been affected by genetic disorders and as a powerful group that can take coordinated action to protect and improve services in a rapidly changing world.

Ann Hunt

Chairwoman of GIG, 1989–1994

GIG Annual Report 1991–92.

At the end of 1992 GIG obtained a grant from the Department of Health for the *Human Genetics Awareness Project*. The project enabled GIG to research, pilot, and produce the various kinds of information which the public needed.

Coming of age for GIG

By 1993, with membership of more than 100 groups, it became clear that GIG had reached a size where it could no longer rely solely on voluntary efforts. A consultation was undertaken with GIG's members and a strategy was adopted for the next few years. The consultation confirmed that what groups really wanted was an organisation was dedicated to policy work in the genetics field.

The overwhelming response from the groups who replied to the consultation had been that GIG should undertake general policy work to improve services for people with genetic conditions

GIG Annual Report 1992–1993.

Director

In March 1993 Alastair Kent was appointed as full-time director on a one-year contract. Initially he worked from home and Patricia van Aardt continued in her part-time role as administrator. GIG had very committed trustees, but they were also fully engaged in the organisations which nominated them. Hiring a director expanded the scope of GIG's work and Alastair Kent was particularly successful at achieving recognition of GIG's role among people and organisations concerned with genetics and in networking with all sectors – public, private, voluntary and so on.

We had someone who was knowledgeable, clever, had the right attitude ... he really got us on the map.

Dee Heaps

GIG Trustee. 1989 – present day

In 1993 GIG sent all MPs information about its work and a copy of its policy statement. It also organised seminars for both GPs and MPs to keep them abreast of new genetics.

A year of change

1993 saw GIG transformed from a charity run by volunteers to an organisation with paid staff preparing to open offices in London. 1993 was also a year full of important scientific development. The gene for tuberous sclerosis was found and preliminary trials of gene therapy for cystic fibrosis began. These were the first exciting steps for individuals and families affected by genetic conditions towards advances which held hope for eventual treatment.

Each new development in genetics brought this field of science and its accompanying ethical, legal, and social issues into the public eye. GIG's work concentrated on balancing worries about genetics – such as eugenics ('designer babies') – with the possibility of developing innovative lifesaving treatments.



Genetic discoveries and their practical health care applications have the potential to transform the lives of many people. At the time gene therapy was a priority issue on many member groups' agendas as they saw its potential as a therapy which might revolutionise families' experience of genetic disorders. GIG's role as educational contact held great importance to see if this type of scientific advancement might translate into viable treatment options. One trustee from this time noted, 'Gene therapy was a big issue for the membership at the time.... If you don't push you don't get'.

In 1993 the first development plan was agreed. GIG rented premises in Farringdon Road, London in 2004. The hard work of the early years paid off and GIG increasingly became a recognised point of contact for patients, support groups, journalists and academics. GIG continued to identify and research issues relevant to the development of genetic services which it then presented in seminars, workshops, and pamphlets.

The growing number of callers to GIG's helpline was evidence of the need for an organisation that undertook this type of work. Patients saw GIG as an organisation that they could turn to for further support. GIG distributed its helpline number to TV programmes and received well over 1,000 calls. Following one programme GIG received more than 300 calls in just a few hours; many callers were unable to get through.

GIG continued to liaise with regional genetic centres and district health authorities as the NHS modernisation plans unfolded. It was of great concern to GIG and its members that many district health authorities did not intend to prioritise genetic services and GIG took this up with the Department of Health.

It mounted a joint conference with the Bio-Industries² to discuss the commercial implications of the new genetics. More than 150 delegates from industry as well as the scientific and medical communities attended. During this time, there was also much interaction with UK Parliament, and the EU on essential issues such as gene patents and screening.

As new groups were formed and others found out about GIG its membership grew. One of the immediate benefits that groups derived from belonging to GIG was that they were no longer alone. They could network with others and get a fresh perspective on their situations and issues. They could keep up with the broader issues effectively. Thus, the voice of patients could be heard collectively, far and wide, without deterring from the daily work and needs of the specific illness.

² Companies that develop biotechnologies “the application of scientific and engineering principles to the processing of materials by biological agents”.

There is no doubt that GIG has helped the organisation I represent. I often hear of events through GIG where I get the opportunity to wear both hats and raise awareness of not only NF [Neurofibromatosis Association] but also all the other conditions GIG represents. I can push NF up the agenda whereas individually people sometimes don't care.

Maggie Ponder

Chair of GIG and Trustee of [Neurofibromatosis Association](#)

Keeping in touch

The diversity of genetic disorders and the diversity of individuals' views is a fact of life; but through its policies, GIG manages to crystallise the 'view of the patient' and to put forward a public viewpoint that all member groups are content to sign up to.

In the *1993–1994 Annual Report* GIG stated that its primary objectives were to:

- improve support and services for people affected by genetic disorders and
- advance the knowledge and understanding of human genetics throughout the population.

All GIG's public work as well as projects such as its seminars for MPs, GPs, and midwives, along with its publications and role as a contact originate from these

primary goals. Throughout GIG's history it has kept its purpose under review, in part by seeking feedback from its members. Questionnaires, mailings, and conferences have allowed members to have their say on what GIG should be doing. So GIG has evolved as its founders envisioned.

GIG grew in [its] initial five years from disparate groups to a flourishing and well-respected network.

Ann Hunt

Chair of GIG, 1989–1994

GIG Annual Report 1993–1994

Funding

What comes first? Is it the need for something? Or the money to get it to be something?

Dee Heaps

GIG Trustee 1989 - present



GIG's funding comes from a variety of sources. Funding from central government, which has included Section 64 funding³, tends to fluctuate with changes in the politics of government. Along with government funding, there are many research foundations which either donate money or collaborate with GIG on various projects, including the [Wellcome Trust](#) and the [Baring Foundation](#).

Money is important for GIG, but independence is precious. While GIG does accept some money from the commercial sector, it takes care not to accept funding if it feels the would-be donor intends to influence policy at GIG.

Nevertheless, because it is the private sector which develops medicines, communication and collaboration with industry are important. The relationship benefits both sides because understanding the needs of patients is vital for commercial industry.

, Since 2005 GIG has been involved with the [Jeans for Genes Appeal](#) as a guest charity and has used some of the funds raised from this to carry out the two-year Family Route Map project. Much of GIG's money also comes with its participation in specific projects.

³ This is funding for voluntary organisations from the Department of Health. It was introduced in 1968 to help groups whose work supports the governments health and social care goals. www.dh.gov.uk

London, new staff: consolidation

With its move to offices in London, the securing of new grants and extra staff. by 1994 GIG was well on its way. In just under five years GIG had moved from a solely voluntary organisation to a charity with a full-time director and four further staff members. GIG now employed a full-time administrator followed by a full-time policy officer in September 1996 – John Gillott – who remained with GIG until the end of 2005. GIG also added a fundraising officer and an advocacy development worker.

In 1996 GIG held further GP seminars which attracted post-graduate education allowance (PGEA) for those who attended. Enquiries from the public increased by 20 per cent and policy work was extended with new funding to employ the full-time policy officer.

Education initiative

In 1995 GIG's teaching pack was in its early stages of development. GIG received funding from The [Wellcome Trust](#) to help Key Stage 4 children (aged 14–16 years old) gain a deeper understanding of the human aspects of genetics – including the ethical, social, and cultural issues. The publication [Genes and you](#) – developed by Gill Mullinar – was published in December 1996 as a ten-unit teaching pack.

The cross-curricular material was designed for teacher use even for those without specialist knowledge. The aims of the pack include: to raise awareness of genetic conditions and their impact of individuals, on families, and on society; to explore human, social, and ethical issues raised by the new genetics; to help students make informed choices.

This publication has been a huge success. More than 10,000 copies were printed and the information is still used today. It is now downloadable on the GIG website where it has been updated with new illustrations and will teach a new generation of teenagers. The education pack even received compliments from a clinician in Russia, which demonstrates potential for widespread use of material of this kind.

I have received your parcel with cross-curricular materials for Key Stage 4 Genes and you by Gill Mullinar. I have no words! It is fantastic! My congratulations on this brilliant volume and two packs of The Science behind Jeans for Genes Day. One can only feel envious. Now it is perfectly clear to me why your doctors and your inhabitants understand the problems of medical genetics and your country has the greatest success in this field of science and medical practice. Again, my cordial thanks.

Dr Medeia Mkheidze M.D. Ph.D

GIG Annual Report 1998 – 1999

With funding from [BBC Children in Need](#) work went ahead to produce materials for children or young people in families where there was a genetic disorder or the risk of one. GIG's publication – *Genetics? What's it got to do with me?* – was the first of its kind, targeting an area that had often been neglected by health professionals as it looked at how the impact of a genetic disorder affects all family members, in particular how siblings may react and their part in the process. This booklet was produced with tremendous input from many individuals and families, who often shared painful personal experiences so that others might be better equipped to cope with the impact that a diagnosis of a genetic condition has on a family.

Disability Discrimination Bill

1995 saw the Disability Discrimination Bill go through Parliament. GIG lobbied MPs to amend the Bill to ensure that people pre-symptomatic for a genetic disorder would be protected against discrimination and GIG's briefings and concerns were extensively discussed at all stages of the Bill. In addition, GIG met with the government minister responsible for disability issues as well as their opposition counterpart. GIG then took the issues to the House of Lords reading.

GIG supported a Ten-Minute Rule Bill⁴ on Insurance and Discrimination put forward by Anne Campbell MP.

GIG emerged as a most effective channel for articulating and communicating the views of those who suffer from genetic disorders or their carers. Both in written and oral evidence GIG made an invaluable contribution to our Report, which Nature, the leading science journal, has described as ‘a wide-ranging report that is likely to have a major impact on Government policies in both Britain and elsewhere’.

Dr Jeremy Bray MP,

GIG Annual Report 1995–1996.

GIG and the media

GIG has always had a good relationship with the media. Journalists view GIG as a place where they can further their understanding about genetics and genetic disorders. In the past professionals dominated stories about the ‘new genetics’ while the voice of those most directly affected went unheard. GIG, acting as an advocate and outlet for the patient, allowed the public to hear the patient

⁴ A Ten-Minute Rule Bill is a type of Private Member's Bill. At the start of public business on most Tuesdays and Wednesdays time is given for a backbench MP to introduce a bill of their own. They may give a speech lasting ten minutes in support of their proposal.



viewpoint. Journalists soon relied on GIG for both accurate science and as a good source for examples of the personal perspective on genetic disease. GIG is one of the first points of contact when genetics makes the headlines.

As early as 1993 articles about genetics – drawn from material provided by GIG – appeared in popular magazines such as *Good Housekeeping* and *Top Sante* as well as in both tabloid and broadsheet newspapers, including *The Independent*, *The Times* and *The Sunday Mirror*. Since then GIG has had front-page coverage in the *Daily Telegraph* (2005) and has been quoted in *The Times* and *The Guardian*. Not only had GIG appeared in the printed press but was also featured on the BBC Radio 2's popular *Jimmy Young Programme*. GIG helped provide background information for a number of other radio and TV programmes about genetics. GIG also appeared on the BBC 1 *Breakfast TV news*, *The Today Programme* on BBC Radio 4 and on Sky News as well as numerous other programmes each year.

Working with the media is an important part of GIG's work. It enables GIG's members to have a voice and helps smaller member groups raise awareness of genetic disorders and spotlight the issues about which they feel strongly.

Personal experiences, channelled through GIG, give journalists a way to illustrate stories that show the implications of genetic research in a more powerful way

than just the research side. The personal stories can often bring an article or TV programme to life and bring the issues to life for a wider audience.

GIG in Europe

While GIG's members are all UK-based charities, the organisation has always been active in Europe. As the UK becomes more involved in the European Union (EU) much of the legislation that affects our members is being dealt with at a European level. Consequently, it is essential that GIG is in Europe to represent its members' concerns. In 1993 GIG was a founding member of the [European Alliance of Genetic Support Groups \(EAGS\)](#), which presents the perspective of patients on genetic issues to European institutions such as the European Commission and the European Parliament. GIG worked with European organisations similar to itself on a project to produce ideas for secondary school texts. GIG has continued to work on numerous projects in collaboration with other countries and national organisations which have been funded by the European Union.

In 1995 GIG was involved in two projects, including the *Concerned Action on Genetic Services in Europe*. This was an examination of genetics in primary care in the EU led by Professor Rodney Harris, Advisor of GIG. Its aim was to develop universal standards to ensure high-quality services for all those who need them. The second project was called *Euroscreen* and was led by Professor Ruth

Chadwick University of Cardiff and Head of Centre for Economics and Social Aspects of Genomics ([Cesagen](#)) This project looked at the ethical, legal and social issues that were being generated at the time by the new genetic knowledge and examined the implications for professionals in a wide range of disciplines.

Genetic services and the NHS

A constant and central area of GIG's work has been to improve NHS services for every patient affected by a genetic condition. NHS objectives include equitable care for all, reduced health care inequality, and to enable patients to be informed about health issues, service options, and to participate fully in personal health decisions. GIG facilitates communication between NHS services and its customers to help all members of society receive equal and quality care. In 1997 GIG set up a clinical audit of the Oxford Regional Genetics Service to look at patients' views of the service. An ongoing forum with users of such services has enabled GIG to see where current genetic services need improvement and then devise the best method to improve the problem.

A major GIG publication – [Guidelines for genetic services](#) – published in the summer of 1998, communicated the public's needs to those responsible for planning, purchasing, and commissioning services. The guide was the culmination of three years of work by a GIG development officer, which

generated mechanisms that enabled services users to identify their needs with reflection of current scientific understanding. GIG also produced [Confidentiality guidelines](#). Publications such as these highlighted the importance of having patient participation in the development of NHS codes of practice.

GIG has always worked closely with research ethics committees (RECs)⁵, to establish the difference between genetic and non-genetic research and how the committees should subsequently respond. While the two kinds of research should be judged by the same standard, the same process should not be used for both. Patients require more involvement in the design of genetic research as the patient's family is directly affected along with the patient; the patient needs to be a decision-maker in the development of treatment. Thus, GIG has helped the REC's understand the uniqueness of research with genetic disorders.

Consortium project

More recently GIG has worked with member organisations to help them help themselves. A project funded in 1998 by The National Lottery Charities Board for three years brought together some of GIG's smaller members to help them collaborate in order to achieve shared goals. Sophie Brown designed small projects among the member groups with the goal of them becoming autonomous

⁵ RECs have been established for many years with the purpose of safeguarding the rights, dignity and welfare of people participating in research in the NHS.

after the project had completed. With this approach, groups took advantage of resources and skills that did not exist within their own organisation.

Examples of the projects which some of the groups carried out together were:

- a leaflet listing questions that parents wished they had asked their consultant or genetic specialist at the time of their child's diagnosis
- a series of training days for medical students to raise awareness of two progressive degenerative genetic disorders.

This project continued into 2000 with further small projects being undertaken in partnership by GIG members, including a symposium on genetic conditions with eye involvement and the development of a 'buddies scheme', which aimed to carry out an accredited training course for those currently without work who could then become buddies for blind or visually impaired young adults, to enable them to participate in leisure activities that would otherwise be denied them.

Orphan medicinal products

This term refers to medicines for rare diseases and genetic disorders that pharmaceutical companies are not commercially motivated to produce, because the market is not big enough to make it worth their while.



In 1998 The European Union proposed regulations for 'orphan medicinal products' and this became law in April 2000. GIG lobbied to ensure that the incentives offered were sufficient to attract the attention of researchers and biotechnology companies to pursue new areas of investigation. The regulations aim to improve the range of treatments for patients with rare life-threatening or serious conditions.

Alastair Kent, GIG's director, was a member of the [Committee for Orphan Medicine Products \(COMP\)](#) and was able to influence the shape of the regulations. GIG members were very concerned that the initial range of incentives proposed would not be big enough to attract anyone into investing in this area.

The regulations are now being reviewed to evaluate their success; in the first five years 22 drugs have received market authorisation, but patient access in various EU countries to the new innovative therapies has often been slow, due to their often expensive nature.

GIG website

In February 1999 GIG launched its website www.gig.org.uk . This was developed by GIG's policy officer and contains current information about genetics as well as links to a wide range of different websites relevant to individuals, families and



organisations seeking information on genetics. People can find new research developments, a specific disorder, download GIG publications, or locate a more appropriate contact, following links to a large number of other sites of organisations with whom GIG may share common concerns.

GIG's website has made the organisation and its policy more accessible to the public by simultaneously bringing attention to specific disorders and educating the public about genetic needs for the future. As GIG's scope expands across the EU and even globally the website has a vital role to play in encouraging the public to become more genetically informed especially as genetics expands further in clinical medicine. Journalists and researchers from the media also consult GIG's site.

The human genome announced

In 2000 GIG celebrated a decade of progress; it was now an established organisation, liaising with medical professionals, legislators and opinion-formers on a regular basis. The year 2000 also marked the mapping of the human genome. In the 10 years or so since GIG had been established, genetics had moved from the search for genes to the search for treatments. This transformation was already benefiting many members and the families they supported.

The year 2000 also saw what has become known as 'The great GM food debate', which gradually drew in human genetics and other related areas of scientific and medical research. This kept GIG busy speaking to journalists and writing articles in papers and magazines which highlighted the benefit of genetic technology.

The Human Fertilisation and Embryology Act was amended in 2001 to include guidelines for the use of embryonic stem cells. GIG, alongside other charities, lobbied hard to persuade MPs and the House of Lords about the potential benefits this research might yield and was delighted when both Houses voted in favour of this amendment by a huge majority. GIG also continued, as it had done for many years, to represent the views of individuals and families on many committees and networks, including the Joint Committee on Medical Genetics of the [Royal College of Physicians](#), the [Royal College of Pathologists](#) and the [British Society of Human Genetics](#). Genetics is at the cutting-edge of scientific discovery and offers one of the most exciting and plausible ways to understand and combat untreatable disease. This possibility keeps GIG and its members alike pushing science to deliver.

*The end is not clear because yesterday's science fiction is
today's paper in Nature is tomorrow's service innovation.*

Alastair Kent

Director, GIG

Recent work

Genetic knowledge parks

2002 welcomed the 'genetic knowledge park' initiatives, which serve as centres of excellence in genetic research. Announced by the then-Secretary of State for Health, Alan Milburn, these genetic knowledge parks are a collaborative effort between universities, the NHS, the commercial sector and patient and consumer interests, aiming to translate scientific research into improved health services. Biotech and pharmaceutical companies stand by and are able to pick up new accessible diagnostic and treatment prospects. GIG was involved in five out of the six successful consortia project bids including London, the North West, Oxford, Cambridge, Newcastle, and Cardiff. As the representative for a spectrum of diseases in these initiatives, GIG quickly made a difference in the public appreciation for the benefit of genetics in medicine.

All this represents a major step forward for GIG and also for our members. Through the Knowledge Parks there promises to be a real opportunity to influence the development of genetic services by the NHS, to interest the private sector in working on the genetic aspects of health which relate to rare and common

disorders and to educate the public about the reality of genetic

disorders and the importance of research and development.

GIG Today Spring 2002

EuroGentest – European Genetic Testing

This exciting project, funded by the EU, is a collaborative effort to seek standardisation and quality improvement in genetic testing. With rapid progress in research there have been many developments involved specifically with genetic tests and the annual growth of patients seeking tests ranges between 100–300 per cent. Genetic services are reaching a higher level of quality, but not all patients experience these advances equally. There is a disparity between member countries of the EU, in particular between western and eastern Europe, and this project seeks to research these differences and ultimately narrow the gap. This project hopes to have an impact on the structure of services and offer guidelines on all aspects of services, from health policy to confidentiality. GIG's task is to look at the information that is given to patients and families about genetic tests and the overall effect on patient education. EuroGentest also seeks to spark off similar initiatives in developing countries and will provide support for such projects.

Research, ethics, and funding

In recent years GIG has become more involved in the issues surrounding patient participation in research. It has worked alongside other organisations, such as the Oxford Genetics Knowledge Park and the Medical Research Council to facilitate investment and to develop methods which are appropriate for researching rarer conditions.

GIG identified that there appeared to be a lack of funding for rarer single gene disorders and Ann Hunt, as a member of the [Gene Therapy Advisory Committee](#) (GAIC), the UK national research ethics committee (REC) for gene therapy clinical research, agreed that many applications were for common complex disorders but not the rarer conditions. Following a survey carried out by Ann Hunt, GIG found a real need for funds in this area. GIG lobbied the Department of Health, with a successful outcome in the White Paper on genetics⁶ in 24th June 2003, in that £3 million was earmarked to fund research into rare disorders, as well as a further £2.5 million for gene therapy into cystic fibrosis.

GIG has worked with other parties, such as research ethics committees to communicate the issues that its member groups face with funding and taking part in research. GIG has also produced publications in this area – [Research and rare genetic differences – frequently asked questions, 2005](#). Genetics is at the forefront of science and often pushes the boundaries of current knowledge in

⁶ Our inheritance, our future: realising the potential of genetics in the NHS

order to move forward in the development of treatments and therapies, this can often mean however that GIG is faced with ethical, social and legal issues and these areas need debating and are looked at with all stakeholders involved. GIG is very aware of the portrayal of the “slippery slope” argument in genetics and it is keen to counterbalance this argument by highlighting the potentials that science can provide to those living with currently incurable, often life threatening disorders.

GIG was very involved in the policy debate surrounding the development of the Human Tissue Bill, which became the Human Tissue Act 2004. GIG helped improve the drafting of this Bill by lobbying parliamentarians in both Houses on a number of issues that were pertinent to its members including lobbying to ensure that the analysis of tissue taken from a patient could be used to benefit a wider range of people, especially blood relatives, this is important because of the familial nature of genetics. This meant that the bill would allow for a wider range of circumstances in which tissues could be used than had been originally specified. Progress was made in both research and clinical issues and the resulting legislation was much improved.

Equal access

In 2001 GIG carried out some research on monitoring methods, to see if different ethnic groups were receiving equal access to genetic services and to put forward



policies which would address this issue. Reporting on its Ethnic Monitoring of Clinical Genetics Project, GIG showed that it is possible to collect data on ethnicity of patients and to monitor equality of access. It also showed that patients from ethnic minority families are not given equal access to cancer services, and put forward recommendations for further data collection which it continues to press for.

The London [IDEAS](#) Genetic Knowledge Park Translation Project is a collaborative project between GIG and the North West Thames Regional Genetic Service, funded by the Department of Health and the Department of Trade and Industry. As there is a lack of information for patients whose main language is not English, IDEAS aims to produce patient info leaflets and audio recordings for the up to 12 of the principal linguistic minorities of London on a variety of topics, including background information about genetics and disease specific information. The project will also promote public and user engagement with the genetic knowledge parks and forge networks with patient support groups. This project is also developing a standardised lexicon of genetic terminology as well as an exact methodology to check translated information.

GIG also has many collaborative projects going on, including work with [GenCAG](#) (Genetics Commissioning Advisory Group) to develop a questionnaire to assess patient satisfaction of genetic centres.

GIG is working with the NHS in the Cancer Genetic Service Development Project to improve access to the quality of genetic cancer services. It has also been quite involved with initiatives to improve professional training. In particular the [PEGASUS](#) (Professional Education for Genetic Assessment and Screening) and Screening Choices projects which aim to generate materials for all national screening services for newborn babies. These projects follow in the lead of the [NHS and Sickle Cell and Thalassaemia Screening Programme's](#) Information for Users and Professionals Subgroup.

GIG's on the committees

A vital way for GIG to keep its members' interest at the forefront of the genetics debate is by representing them on influential committees. GIG staff members, including the director Alastair Kent and programme manager Pritti Mehta, sit on many committees about genetics; through these they are able to make an impact, keep current with the most recent news, and be active in those discussions where priorities are being decided upon.

GIG's activities have increased the representation of patient groups across key national and governmental bodies. In 2005 The Genetics Commissioning Advisory Group (GenCAG) was set up to examine the variations in quality and accuracy of the genetic tests throughout the UK and GIG was asked to join.



Through GenCAG, GIG will look at ways of shaping a nationwide genetic testing network.

GIG in the future

There is always going to be a need for a coherent articulation of patient and family interests in relation to genetics.

Alastair Kent

Director, GIG

With the development of the genetic knowledge parks and as a result of a consultation with GIG member groups which was funded by a grant from the Baring Foundation, several new posts were created. The team grew to include a communications officer, an assistant director, as well as regional staff based in Wales and Scotland. There are hopes to set up a similar post in Northern Ireland.

GIG's work with the media steadily increases and behind the scenes GIG has helped many of its member organisations gain media coverage on programmes ranging from *This Morning* on ITV to *Breakfast News* on the BBC.

GIG Director, Alastair Kent, advances GIG's scope and influence in the UK abroad through his membership and commitment to committee work. As a result



of this work, GIG has been at the forefront of significant genetics legislation in both the UK and the EU.

In 2005 GIG had its first ever artist-in-residence, based at the [North West Genetics Knowledge Park](#) in Manchester, who made a remarkable impact on the local community by visiting schools and colleges and helping to widen peoples perception of genetics and art. She also worked with some of the local patient support groups to organise workshops using a variety of different mediums, including puppetry, music and poetry. GIG hopes that its artist will help to articulate its mission to a new audience.

As genetics becomes part of mainstream medicine with links to many common disorders such as cancer, diabetes and heart disease, GIG's sphere of influence widens. In the future GIG will be an even more indispensable body working on a broad spectrum of conditions. Its core members will always remain the groups helping people who have rare disorders; they are the organisations that need the help and support that GIG can provide. GIG will continue to contribute to government policies, by speaking on behalf of members who may not have a voice on their own and will go on working with different kinds of professionals, ranging from those in academia to commercial companies to law-makers. It will continue building on the foundations it has so carefully created.

Fundamentally GIG will remain a policy organisation setting an agenda, at the very least reacting to current issues and ideally predicting them...

John Dart Director, [DEBRA](#) and Trustee of GIG

Going global?

GIG's director attends conferences throughout the world and this has given GIG exposure in the global arena. Alastair Kent brings news and exciting developments from other areas of the world and in turn takes part in some significant initiatives. In Autumn 2005 GIG signed up to a manifesto aimed at persuading the World Health Organisation to take action on birth defects. GIG reviewed a [March of Dimes](#)⁷ [Global report on birth defects](#) and has since sent copies to our government to raise the issue with the appropriate title holders.

GIG is also working alongside researchers and funding agencies from Canada, China, Japan, Nigeria, and the United States on the ethical, legal, and social aspects of the [International HapMap Project](#), which is mapping sets of inherited characteristics known as haplotypes. This project aims to provide a public resource which might simplify the search for diseases linked to particular gene sequences and perhaps to therapies.

⁷ March of Dimes is a US charity whose mission is to improve the health of babies by preventing birth defects, premature birth and infant mortality. www.marchofdimes.com

GIG has also worked with the Genetic Alliance – a sister organisation in the United States – on issues related to quality in genetic testing services along with equity and fairness of access. While GIG will always participate in activities along these lines, it will be selective about this and will tend to keep its work centred in the UK unless a need for expansion arises as with Europe because of the implications EU policy has on health issues at home.

The driving force behind every GIG initiative is the well-being of patients; this includes all aspects of health from the social implications of living with an illness to disease research and receiving quality healthcare. Reaching these goals requires collaboration among doctors, academics, industries, and policy-makers. While GIG adds weight to the views of its members it is a relationship with constant review on its position and it is the members' contribution which brings credibility, influence, and external recognition to GIG. Thus, GIG is successfully able to gather a coherent policy for its members and use its credibility to influence improvements in the care of patients.

When GIG was still just forming, Ann Hunt asked, 'the debate on the ethics of genetic engineering is at present conducted by philosophers, doctors, and journalists. Do the views of sufferers and their families have a place in the debate? Are we too close to the problem to see the wider issues?'



GIG has found a place in the debate and has indeed given patients and their families a significant voice on the wider issues. It has evolved into an organisation which has a huge impact on policy and legislation in the UK, Europe, and the world.

Consulting patients has emerged as indispensable in this field and today it is almost unthinkable for the Department of Health to create any consulting groups on genetics without patient representation; much of the time this representation is through GIG.