



Annual Report 2003 - 2004



Keeping up the pressure

A message from the chair

This has been a very busy year for GIG. Our membership is increasing year on year and I welcome all our new members. To cope with the increasing workload we now have more staff. Working both with and within the regional Genetic Knowledge Parks in England and Wales and the Centre for Medical Genetics in Birmingham we are now much better placed to be active all over the UK. Despite much effort we still do not have a presence in Scotland. Raising the funds for a Scottish post has been a priority and will continue to be so in the forthcoming year. Once we have achieved this aim we will then focus on Northern Ireland so that we can be truly representative of all our members wherever they live within the UK.

The science of genetics is becoming an integral part of most areas of medicine. Many common disorders are now known to have some genetic basis mixed in with other causative factors. Whilst the main focus of GIG's work is to represent and support people with rare single gene disorders we now find an increasing need to take a role in issues that are important for those affected by the more common complex disorders. This is a challenge, but one that the GIG team, led by Alastair Kent, has risen to and I would like to thank them all for their hard work.

Even though we are extending our work to more conditions we are still an organisation that focuses on issues that are important

for affected people and their families. Many official bodies recognise that GIG is truly representative of its members. I believe this is why we are so often included in consultations and are able to make an impact.

We have only been able to increase in size because we have been able to raise sufficient funds. The larger we are the greater the task of making sure we have a sound financial footing. Fund raising is always a challenge and I would like to take this opportunity to thank all the grant giving trusts, organisations and individuals who have supported us so generously.

Maggie Ponder
August 2004

Highlights of the year

- ☞ For the first time in its history GIG's income has risen to just over £300,000.
- ☞ GIG played an active role in the work of two Department of Health policy groups. The Genetics Commissioning Advisory Group (GenCAG) and the UK Genetic Testing Network Steering Group (UKGTN).
- ☞ GIG is representing the patient viewpoint on the Ethics Committee of the International Haplotype Mapping Project.
- ☞ GIG's membership continues to rise.
- ☞ The GIG website is now receiving between 10,000 - 12,000 hits a month
- ☞ The GIG website has been completely re-designed, making it more accessible.
- ☞ Genes and You, GIG's successful teachers pack, will be made available online with newly commissioned artwork.

- ☞ GIG representatives have given over 40 talks from California to Cracow!
- ☞ GIG has been able to provide ways for at least three projects of national significance to engage directly with individuals and families affected by genetic disorders
- ☞ GIG is working collaboratively with the Genetics Knowledge Parks throughout the UK.
- ☞ GIG was involved in the production and dissemination of a departmental leaflet for patients referred to Clinical Genetics in Birmingham.
- ☞ Genes Day at the Thinktank in Birmingham attracted over 2,000 visitors!

and much, much more!

Introduction

“May you live in interesting times” is said to be an ancient Chinese wish. When looking at the past year this is certainly something that has been true for the Genetic Interest Group (GIG) and the organisations of patients and families affected by genetic disorders from whose perspective GIG speaks. Genetics has rarely been far from the front pages as the implications (real or imagined) of new discoveries and developments provide rich pickings for print and broadcast journalists alike.

Away from the media spotlight, understanding of the links between our genes and our health, and the diseases which mutations cause or to which they predispose us has been steady, and there is light at the end of the tunnel for a growing number of families where there is now at least a prospect of treatment being developed. Of course for very many more there is still little or nothing that can be done to avert or prevent the onset and progress of their disease. This is why support for high quality biomedical research and the transfer of the results of this endeavour into products and services will continue to be one of GIG’s highest priorities, and why we will oppose and resist those who would put obstacles in the way of the progress demanded by our members and the families they represent.

Partnership

An enduring theme of Government announcements during the year has been the need for the patient voice to be heard by professionals involved in the delivery of services by the NHS. Partnership not paternalism has been the message – something which we have been quietly getting on with for many years. Right from the start, GIG has worked alongside colleagues in clinical medicine, research, industry and policy to make sure that our members’ voices are heard by those with the power and resources to influence change. So, when patient participation in health care moved up the political agenda GIG was already ahead of the game, with a seat at the table of many of the meetings where policy making and planning was taking place.

GIG has played an active role in the work of two of the Department of Health’s key policy groups – the Genetics Commissioning Advisory Group (GenCAG) and the UK Genetic Testing Network (UK GTN) Steering Committee. This latter body is responsible for overseeing the transfer of newly developed genetic tests from research laboratories into clinical services and for making sure that access to these tests is equitable wherever you live in the UK. Although progress with this has been slower than we would like (due to the devolution of power by the Department of Health to more local commissioning bodies and the variations in practice across the country) the foundations have been laid, and in the coming years we should start to see real progress.

During the year we have continued to make active inputs to the work of other bodies including the Human Genetics Commission, the Human Fertilisation and Embryology Authority, professional groups such as the Joint Committee on Medical Genetics of the Medical Royal Colleges, and industry and commercial associations such as the Association of British Insurers and the Bio Industry Association.

Although partnership is central to our philosophy, at all times we are careful to avoid becoming too closely identified with the specific interests of any vested interest or grouping. Every step of the way we emphasise that we are there for our members, we put across their perspectives and concerns, and promote their interests.

GIG and its Members

GIG derives its legitimacy and its authority from the relationship that it has with its member groups and the trust and confidence that they have that we will speak from their perspective. Keeping our members engaged is, and will always be, a high priority for us.

Our membership continues to grow. We now have over 130 groups in membership, representing the entire spectrum of genetic disorders and ranging from very large organisations with hundreds (if not thousands) of staff to tiny groups which exist

because of the effort of dedicated volunteers, many of whom are affected by or are carers of someone with a very rare genetic condition.

Our newsletter, “GIG TODAY”, continues to increase its circulation, frequently attracting articles and announcements from members anxious to share their news with a wider audience.

GIG staff and trustees are regularly invited to make an input to members’ conferences. We have also exhibited at a number of conferences and meetings during the year including that of the London IDEAS Genetics Knowledge Park and the European Society for Human Genetics. These meetings are an important way of reaching a wider audience, making sure that they are aware of the impact of genetic conditions, and of the work that is done by voluntary groups to support those affected by them.

Reaching a Broader Public

During the year the number of visitors to our website continued to grow. Every month between 10,000 – 12,000 visitors log on in search of information and comment. To make the website more accessible it has been completely re-designed, and it now includes even more useful information including the responses that GIG has made to government and other bodies on policy

matters, and copies of our publications in a downloadable format.

A major addition to our website in the coming year will be an electronic version of our genetics teaching pack, “Genes and You”, designed for 14 – 16 year olds. First produced a few years ago, over 8000 copies of the paper version of this pack have been sent out to schools and colleges. Now a new version, with specially commissioned illustrations and interactive features, is being prepared for publication on the web. This will extend its impact even further.

GIG has also produced a number of other publications during the year. These have addressed a variety of topics including the importance of diagnosis as a means to get access to treatment (where possible) and other forms of support.

GIG’s contacts with the media are very well developed. We regularly brief journalists and media researchers on issues relating to genetics stories, and we are frequently called on to give interviews and provide comments to newspapers, radio and television in the UK and further afield.

GIG’s spokespeople have appeared on national TV and radio, on local stations and in print in the broadsheets, the tabloids and special interest magazines. Articles by GIG staff have also been

printed in peer review journals and in a range of popular magazines.

National and International Issues

Genetics has always been an international activity. Today developments in one part of the world can quickly affect prospects for patients and families in another who are anxious to see research progressing and treatments moving closer.

The Committee for Orphan Medicinal Products (COMP), part of the European Union’s system for licensing new medicines for rare disorders, has now recommended official recognition for nearly three hundred products, aiming to provide treatments for rare disorders (ie those affecting fewer than 5 in 10,000 in the EU). About 15 of these have already been developed into licensed therapies for a range of different disorders. GIG is represented on this body, one of only two patient groups to be appointed as a member of this committee throughout the whole of the EU.

Genetic testing also came under the spotlight of the European Commission and a high level working group was set up to look at issues raised by developments in genetic testing across the EU. GIG provided one of only three patient representations on this body, which was able to take evidence from a number of senior figures from industry, medicine, science and public

policy as well as inviting comments from patient groups and the disability movement. A report with 25 different recommendations on the development of genetic testing across Europe was launched at a major conference in Brussels attended by over 600 people in May 2004.

This was not the only conference where GIG had a high profile during the year. GIG provided speeches at a wide range of meetings in the UK and further a field from California to Cracow!

Over forty speeches and many more informal talks were given by GIG staff and trustees to large and small audiences here in the UK and overseas. GIG speakers have shared platforms with government ministers, Nobel laureates and captains of industry in order to get across the message from our members.

Equity

An unshakeable commitment to equity of access to the benefits resulting from advances in genetic knowledge has been a central part of GIG's philosophy and strategy, and this commitment continues unabated today.

During the year we completed a two year study designed to examine the recording of the use of the NHS's genetics services by people from minority ethnic groups. This showed that these

services were used significantly less by minority ethnic groups than would have been expected, and that the recording of the ethnicity of service users by NHS genetics centres was at best very patchy. It is clear that if records were not kept then underuse by minority ethnic groups would not be noticed and action would not be taken to correct it. As a result of this project we have been successful in securing further funding from the Department of Health to help NHS genetics centres in England produce recording schemes and to train the relevant staff in their use.

GIG is also working on a related project as part of its collaboration with the London "IDEAS" Genetic Knowledge Park. This will see the production of literature on genetic issues relevant to patients using genetics clinics in a range of different minority languages, these will include Gujarati, Punjabi, Sylheti/Bengali, Turkish and Arabic which will be published and distributed during the coming year with more to follow in due course. Our work in this area was greatly assisted by the efforts of three students on placements during the year: - Parul Vansadia and Kavita Sangha from Brunel University and Meredith Carter from George Mason University, USA.

Because of the expertise developed in this field GIG's Project Manager also acts as an advisor to a number of other national committees and bodies on ethnicity issues including the

National Autozygosity Mapping Project and the Haemoglobinopathy Steering Committee Information Group.

Providing Access to Expertise

During the year GIG has been able to provide ways for at least three projects of national significance to engage directly with individuals and families affected by genetic disorders. A number of our members identified families willing to be interviewed for a project looking at genetics in primary and secondary care carried out by the School of Health and Related Research at Sheffield University. We were able to provide patients and family representatives for a series of workshops convened by the Public Health Genetics Unit and the Cambridge Genetics Knowledge Park to identify the educational needs of non-specialist doctors, health service managers and other NHS professionals. As a result the recommendations were grounded and reflected the real life experiences of service users.

The third project that GIG was involved in was the use of community based focus groups from specific ethnic groups to test out the accessibility of information to be provided to those for whom English is not their first language. This proved to be invaluable as a means of checking the relevance and the accessibility of the information and the methodology developed by GIG is likely to be taken up by others.

GIG and the Genetics Knowledge Parks

GIG has close association and works collaboratively with the Genetics Knowledge Parks (GKPs) and other centres of excellence within the UK including the Oxford Genetics Knowledge Park, the London “IDEAS” Knowledge Park, The Wales Gene Park, the Manchester “NoWGEN” Genetics Knowledge Park, the Cambridge Genetics Knowledge Park and the Centre for Education in Medical Genetics at Birmingham. During the past year, GIG has organised meetings involving personnel from these centres and GIG’s London based staff (which also include individuals with specific ties to Oxford and to London IDEAS). GIG identified a need to bring everyone together to discuss issues of common concern and to share each other’s activities and interests, and also the activities and interest of each others’ host organisations.

Experiences and expertise in particular areas of common interest have been discussed and shared. Topics have included fundraising, communication between individuals and between the host organisations; issues around access to information about human genetics and genetic conditions.

It soon became clear that such meetings should not just be confined to those individuals and organisations with whom GIG has direct associations and so invitations to these meetings have been extended to people from the centres of excellence

mentioned previously and beyond (including the Centre for Life at Newcastle). The meetings have become larger and deal with an ever-widening range of human genetics-related issues and have helped to ensure a coherent and consistent message about the work of all these centres to the public and to those with an interest in specific aspects of their work.

GIG in Wales

GIG's Development Officer in Wales is based at the Wales Gene Park. She is working with healthcare professionals at the Wales Medical Genetics Service, Researchers from Cardiff and Glamorgan Universities and most importantly meeting families and groups across Wales.

An important part of the work over the past year has been GIG's involvement in the team allocating the extra funding (£1.5million) from the Welsh Assembly to the Genetics Service. This money will strengthen existing services across Wales and provide new areas of clinical speciality and expertise. In the coming year we will be keeping a high profile at the Assembly for continued support of genetics services to families.

GIG has also been working with the Wales Neurological Alliance to input on the Assembly's Review of neuroscience services. By having a strong voice from those who use existing services and need new services, we are able to ensure important

issues are properly addressed. This alliance will continue working throughout next year. We also plan to develop a strong presence at the annual political party conferences.

This year has been all about meeting people and planning what we can do together to help families across Wales.

GIG in the West Midlands

GIG's Development Officer in partnership with colleagues from the West Midlands Clinical Genetics Unit have started to lay the foundations for a strategy to support the involvement of patients and the public in the planning, design and improvement of local genetic services. Priorities under the headings of Awareness, Education and Partnership were identified. These are not exclusive but "interwoven" and inseparable. In order to translate the strategy into action we: -

- Attended and presented at Professional and Family Workshops organised by GIG member charities, such as the Fragile X Society and the Retinoblastoma Society. This experience has been invaluable, both in building relationships and a knowledge base for the work of these charities and in understanding the affects genetic disorders can have on families.
- Were involved in the production and dissemination of a departmental leaflet for patients referred to Clinical Genetics

Services. This led to the further development of an Urdu version of the leaflet and an audio tape in Urdu. Ongoing evaluation using Focus Groups is now being planned to establish patient information needs.

- Developed a partnership with Thinktank, Birmingham’s Science and Discovery Centre, that led to a successful public engagement event “Genes Day” at Thinktank in October 2003 attracted over 2,000 visitors.
- Embarked upon a project to produce video captions of patients discussing their genetic condition and how this affects their individual and family life. This project is in the planning stage and patients will be invited to help in the education of healthcare professionals enabling them to gain a greater understanding of, and improve, the way in which services are provided.

Building on the work already completed, future work around engaging the community in debate about genetic issues will serve to create a two-way communication flow and a mechanism for influencing policy both locally and nationally. The foundations are in place to move toward an inclusive and patient-centred clinical genetic service and this has paved the way for the continuing development of GIG’s work. In future, individuals with genetic conditions and their families will not only have a significant role in shaping and planning the way

services are delivered but also in how medical education in genetics is developed. To do so people will need to be enabled and supported, allowing their involvement to be meaningful and effect change.

Ethical Matters

GIG has played an important role in voicing ideas and views from our members on the ethical implications of developments in genetics, and especially in drawing attention to the possible impact of preventing research and development from advancing by putting unreasonable barriers in the way.

A number of our members have experienced difficulties in getting research projects they have funded under way because research ethics committees appeared not to appreciate the special circumstances underpinning research into rare genetic disorders. We convened workshops to discuss the problems identified and as a result will be producing information for ethics committee members on these issues which address this question from the families’ perspective and which will lay out concerns and support a way forward. This will be followed up with training for REC members later in 2004 / 5.

But it is not just at local level that GIG is addressing ethical questions and arguing for members’ interests. GIG is also represented on the Ethics Committee of the International

Haplotype Mapping Project – a multi million pound project which aims to examine genetic diversity and link it to patterns in important diseases - and the “P3G” consortium, which is developing standards of good practice for population genetics studies being carried out with public funding.

Setting the Agenda

Looking ahead we can identify a number of issues that will have an impact on GIG, on the organisations that belong to it and the individuals and the families they represent and support. Genetics shows no sign of dropping off the political and the public agenda, and several proposed developments may have significant impact – though whether this will be positive or negative remains to be seen.

In 2004 the Human Genetics Commission and the House of Commons Select Committee are both undertaking consultations on genetics and reproductive technology. In 2005 the Human Tissue Bill will become law, and a new Human Tissue Authority set up – though this will be combined with the Human Fertilisation and Embryology Authority to form a single regulatory body. Issues such as the use of human embryonic stem cells for the development of therapies, the role of animals in biomedical research and funding of new medicines for the benefit of patients with rare genetic disorders will continue to require sustained input from the GIG team. Doubtless other

issues, at home and abroad, will also assume priority in the light of changing circumstances, and GIG will continue to play its part in ensuring that all the needs and views of its members are heard loud and clear in the resolution of these issues. But we are not just reactive. Our trustees will review our strategy at regular intervals in the year to come so that we can be confident that we are pushing out the boundaries on behalf of all our members, helping to raise awareness of the impact of genetic conditions on families and individuals and pushing for the speediest possible response by government, the NHS and anyone else with the power to improve our members’ situation as new opportunities arise.

Extract of Audited Accounts.

Incoming Resources	Total Funds 2004 (£)	Total Funds 2003 (£)
Membership	30,639	17,350
Grants and Donations	297,655	259,957
Meeting and Receipts	1,160	-
Sundry Income	90	439
Bank Interest	8,594	6,459
Total Incoming Resources	338,138	284,205
Resources Expended	(£)	(£)
Direct Charitable Expenditure	219,046	191,243
Fundraising	9,036	5,010
Management and Administration	47,273	37,929
Total Resources Expended	275,355	234,182

Major Donors

	(£)
Amersham	2,000
Association of British Insurers	10,000
Association of British Pharmaceutical Industry	5,000
AstraZeneca	15,000
Birmingham Women's Hospital	4,000
BUPA	2,500
Cambridge Genetics Knowledge Park	6,000
Department of Health (S64 core grant)	20,000
Department of Health (S64 project grant)	7,500
European Diagnostics Manufacturers Association	5,995
Genzyme	4,000
GlaxoSmithKline	10,000
King Baudouin Foundation	17,602
London IDEAS Genetic Knowledge Park	41,391
Medical Research Council	32,235
NHS (Research and Development Fund)	41,250
Novartis	27,000
NoWGEN (North West Genetic Knowledge Park)	10,000
Oxford Genetics Knowledge Park	10,000
Royal Logistics Corp Band	1,000
Wellcome Trust	20,149
Other donations	5,033
Total	297,665

GIG's Money

2003 – 04 has seen a significant rise in our income. For the first time this has topped £300,000. We are very grateful for the support of all who fund us. A special word of thanks is due to our regular supporters. Their commitment gives us a degree of security that enables us to plan and act strategically. This has to be in the best interests of our members.

Looking ahead we can see signs of turbulence. Fundraising seems set to become more difficult as charities compete more vigorously for the available resources and these fail to keep up with demand.

We are putting additional effort into our fundraising in order to secure the resources we need, and to enable us to continue to develop in the year to come.

As always, GIG is careful to preserve its independence and its autonomy. Money which might be offered with unacceptable conditions attached would be refused. GIG sets its agenda and its strategy, then seeks the resources to put this into practice. We will not allow ourselves to be led by money into positions which are not in the interests of those living with genetic disorders, their families and the groups they choose to join.

The figures on page 12 are extracted from the full accounts audited by MacIntyre Hudson (Chartered Accountants and Registered Auditors). These accounts are certified to give a true and fair view of the state of affairs of the Genetic Interest Group as at 31st March 2004.

Board of Trustees

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Professor Rodney Harris
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Director

Alastair Kent, Director

The GIG Team

Anna Lane, Development Officer (based in Birmingham)

Buddug Williams, Development Officer (based in Wales)

John Gillott, Policy Officer

Lucy Ullmann, Finance and Fundraising Officer

Max Ullmann, Administrator (part time)

Melissa Winter, Membership and Communications Officer

Pritti Mehta, Project Manager

Tom Barclay, Assistant Director

Members

Aarskog Syndrome Support Group (UK)

ADHD National Alliance

Adrenal Hyperplasia Network

Adrenoleukodystrophy Family Support Group

Albinism Fellowship

Alkaptonuria Society

Alpha 1 Support UK

Alstrom Syndrome UK

Alzheimer's Society

Androgen Insensitivity Syndrome Support Group

Aniridia Network UK

Anorchidism Support Group (ASG)

AnteNatal Results and Choices (ARC)

Assert (the Angelman Syndrome Support Group)

Association for Glycogen Storage Disease (UK)

Association of Multiple Endocrine Neoplasia Disorders (AMEND)

Ataxia - Telangiectasia Society

Ataxia UK

ATRX Support Group

Barth Syndrome Trust

Batten Disease Family Association

Beckwith-Wiedemann Support Group

BEHCETS Organisation

British Heart Foundation

The British Porphyria Association

British Retinitis Pigmentosa Society

Cancer Research UK

Cardiomyopathy Association

CDLS Foundation (Cornelia De Lange Syndrome)

CGD Research Trust (Chronic Granulomatous Disorder)

Childhood Eye Cancer Trust (CHECT) (for families and individuals affected by retinoblastoma)

Children's Mitochondrial Disease Network, The

Children Living with Inherited Metabolic Diseases (CLIMB)

CMT UK (Charcot-Marie-Tooth Disease)

The Cogent Trust

Cohen Syndrome Support Group

Congenital Adrenal Hyperplasia Support Group

Contact a Family (Scotland)

Costello Support Group
 Cri Du Chat Syndrome Group
 The Cystic Fibrosis Trust
 Dariers Disease Support Group
 DEBRA (National charity for Epidermolysis Bullosa EB)
 Diabetes UK
 Down's Heart Group
 Dyskeratosis Congenita Society
 The Dystonia Society
 East London Branch Sickle Cell Society
 Ectodermal Dysplasia Society
 Ehlers-Danlos Support Group
 The Eyeless Trust
 The Fragile X Society
 FSH Muscular Dystrophy Support Group
 FSP Support Group
 Fuchsfriends UK
 Galactosaemia Support Group
 Gauchers Association
 Gene Aid
 Gorlin Syndrome Group
 Gwent Huntington's Disease Association Support
 Haemochromatosis Society
 Haemophilia Society
 Headlines Craniofacial Support
 Heart Haven
 HITS (UK) Family Support Network

HME Support Group
 Huntington's Disease Association
 Huntington's Disease - Scotland
 Huntington's Disease Association (Colchester Branch)
 The International Autistic Research Organisation
 International Glaucoma Association
 The Jennifer Trust for Spinal Muscular Atrophy
 Klinefelter Organisation (UK)
 Laurence Moon Bardet Biedl Society
 Long QT Family Support Group
 LOOK (National Federation of families with visually impaired children)
 Macmillan Cancer Relief
 Manchester Sickle Cell and Thalassaemia Centre
 Marfan Association UK
 Motor Neurone Disease Association
 Muscular Dystrophy Campaign
 Myotonic Dystrophy Support Group
 Narcolepsy Association - UKAN
 NASPCS (charity for uncontinent and stoma children)
 National Sickle Cell Programme
 The Neurofibromatosis Association
 Niemann-Pick Disease Group
 NPS (UK) (Nail Patella Syndrome)
 NSPKU (for those with Phenylketonuria PKU)
 Nystagmus Network
 OSCAR (Organisation for Sickle Cell Anaemia – Reading)

Osteopetrosis Support Group
Pemphigus Vulgaris Network
Peutz Jeghers Syndrome Support Group
PKD Charity (Polycystic kidney disease)
Prader Willi Syndrome Association UK
Primary Ciliary Dyskinesia Family Support Group
Primary Immunodeficiency Association (PIA)
Progressive Supranuclear Palsy Association
Psoriatic Arthropathy Alliance
PXE International
The Pseudoxanthoma Elasticum (PXE) Support Group (PiXiE)
Restricted Growth Association
Rett Syndrome Association UK
SADS UK (The Sudden Adult Death Trust)
Seriously Ill for Medical Research
Shwachman Diamond Support Group
Sickle Cell and Thalassaemia Service
Society for Mucopolysaccharide Diseases
SOFT UK (support organisation for Trisomy 13/18 and related disorders)
SPECS (specific eye conditions alliance group)
STEPS - Association for People with Lower Limb Abnormalities
Stickler Syndrome Support Group
Syndromes Without A Name (SWAN)
Tay Sachs and Allied Diseases Association
Telangiectasia Self Help Group

Tuberous Sclerosis Association
Turner Syndrome Support Society (UK)
UK Thalassaemia Society
Unique - The Rare Chromosome Disorder Support Group
Williams Syndrome Foundation Limited
Worster Drought Syndrome Support Group
XLH Network
XP Support Group



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