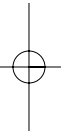
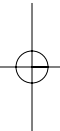
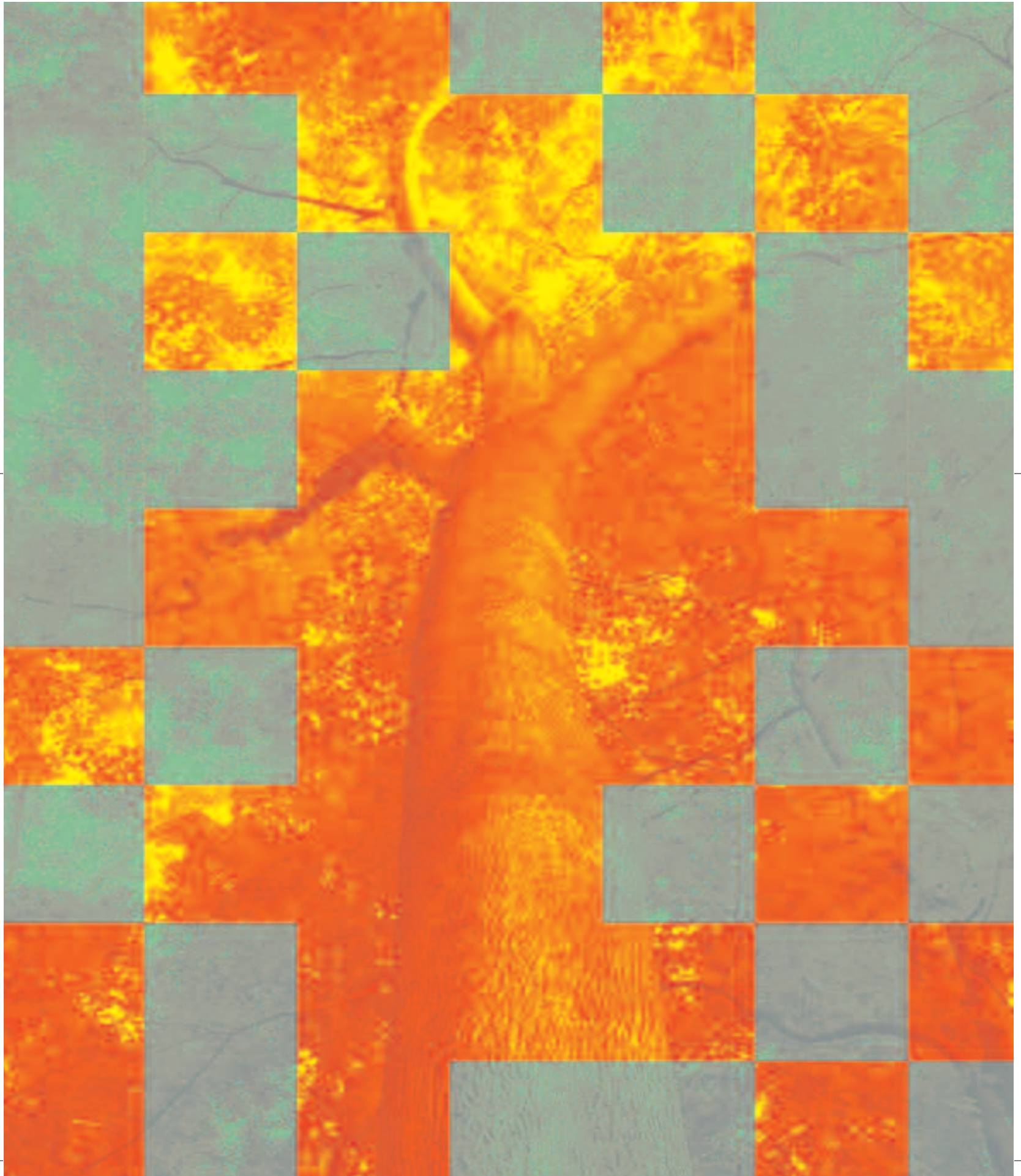
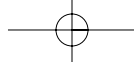
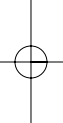
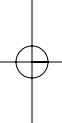
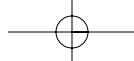


# Delivering the Message

Genetic Interest Group Annual Report

2004 - 2005





## Delivering the Message - Annual Report 2004 - 2005

### A message from the Chair - 2005

It is a pleasure to note that yet again we have increased our membership and I would like to welcome all members. During this year GIG has continued to expand the range and amount of work that is done. More members and more work has meant more staff. We have 3 new members of staff who have joined the team this year: Helen Roden who is Office Manager, Celine Lewis working on the Eurogenetest project and Nick Meade who is developing the work on delivery of services to all ethnic groups in the UK. Welcome to them all.

As you read this report you will see the very wide variety of activities that we are now engaged in. All are aimed ultimately at improving the lives of people and families affected by genetic disease. As an umbrella group we are able to act as the voice of our members and increasingly I feel we are being listened to. I am particularly pleased that we have finally managed to secure funding to allow us to have a post in Scotland. This means that from next year we will be able to extend our activity to Scotland as well as England and Wales. Of course many issues are universal but each of the home nations has some different laws and policies and having a dedicated member of staff is very important. Now all we need is to try and set up something specifically for Northern Ireland.

As the work of GIG has expanded so has the complexity of the administration required to support all our activities. Our staff have risen to this challenge and behind the scenes much has gone on to ensure that the charity continues to be managed properly and that we have systems in place so that we

continue to work efficiently on behalf of our members. We feel it is now time to move to become a company limited by guarantee and work is in hand to do this. This change will in no way alter the nature of what we do or who we are. It will however, make us more secure and make life easier when dealing with contracts and agreements with funding organisations.

This has been a good year and I anticipate that the next will be even better. We have a really good team of people working for us and I would like to thank them all. I would also like to thank my fellow trustees for all their help and support. Particularly I would like to thank John Gluckstein, our honorary treasurer, who has decided it is time to retire. He has been the treasurer since the beginning of GIG and has given an enormous amount of time and effort. His guidance and expertise have been invaluable and we will miss him.

GIG relies on being able to raise sufficient funds. We are very grateful to all those individuals, grant giving trusts and organisations who have so generously supported us this year – thank you all.

**Maggie Ponder**  
Chair  
July 2005

## Delivering the Message - Annual Report 2004 - 2005

### Highlights of the Year

- GIG appointed its first ever "Artist in Residence", Sayward Morley based in Manchester.
- Visitors to our website ([www.gig.org.uk](http://www.gig.org.uk)) doubled to over 20,000 per month.
- The GIG stand at The British Society for Human Genetics (BSHG) Conference in York (another first) proved enormously popular with delegates.
- GIG launched its "Beacon Projects" on ethnic monitoring in Liverpool and Devon and Cornwall.
- Lobbying in Parliament helped to amend the Human Tissue Bill to improve opportunities for our members to access services and participate in research.
- Advice to UK Biobank helped promote understanding and awareness of how this multi-million pound project is perceived.
- GIG's input to the assessment of genetic services quality in the NHS helped ensure that equity and access is improved for all sections of the community.
- New standards of good practice for translating genetic information into other languages were developed under GIG's leadership.
- GIG speakers delivered academic papers and popular talks at conferences from Wolverhampton to Western Australia.
- Membership increases steadily year on year.
- The National Centre for Genetics Education in the NHS added GIG's Development Officer to its advisers ensuring a patient and family perspective in all the courses developed.
- Eurogentest, a pan-European Network of Excellence starts with GIG as a Unit Leader, developing quality standards for information to patients and families.
- Partnership with the Genetic Knowledge Parks continued to deliver new ways of reaching out to the wider public on the benefits arising in genetic research.
- GIG staff have contributed to a wide range of consultations for bodies such as the Human Genetics Commission, the Human Fertilization and Embryology Authority and the Science and Technology Select Committee of the House of Commons.
- GIG's membership of the Department of Health's key genetic committees (GenCAG and the UKGTN) made sure that our members' point of view informs service development and policy in NHS genetic services.
- GIG was included in the decision making process of how to best use the £1.5million additional money for the Medical Genetics Service for Wales from the Welsh Assembly.
- GIG is a partner in the NHS Genetics Education Centre's 'Telling Stories' project - a website that will help nurses understand about the effects of a genetic condition. Funding from the Wellcome Trust allows this important project to go ahead.
- Working within the Wales Neurological Alliance to provide a patient and family voice into the Welsh Assembly's Review of Neurological Services.
- Membership of the Advisory Committee of the ESRC genetics and genomics centres links social scientists with families and helps to ensure that research is targeted and appropriate.
- The family perspective on genetic issues has been promoted widely through GIG's extensive contact with the press and media.
- Despite a difficult financial climate GIG's income increased over the year enabling us to expand our activities and improve our impact on behalf of all our members.



## Delivering the Message - Annual Report 2004 - 2005

### Introduction

For years now patient organisations have been pointing out to doctors, policy makers and those in government that their plans would be better informed and more likely to reach their targets if they were formulated and delivered with patients as partners in the process, not just as recipients of the plans and schemes devised by others for our benefit. Now, at last, the message seems to be getting across and the Genetic Interest Group, alongside others representing patient and family interests, is increasingly becoming involved as a real partner working alongside other professionals, policy makers and parliamentarians.

This is good news for the groups that make up our membership, and for the individuals and the families that they support. It means that their voice is contributing to the discussions about the links between our genes and our health or disease at the highest levels; we are able to contribute to discussions at many levels both in the UK and further a field. This is right and proper, but we never forget that it is because of the links we have with our members that we have earned this access, and it is their needs and wishes that we are bound to input to this process. GIG's trustees, elected by and representative of our membership are the guarantors that the link with our members remains fundamental to the work we do.

### Links with our Members

Melissa Winter, GIG's External Communications and Membership Engagement Officer, has been busy strengthening links with members. We have been pleased to be invited to take part in an increasing number of conferences and meetings organised by our member groups, usually to discuss matters of policy or legislation, for example Association of Multiple Endocrine Neoplasia Disorders (AMEND) The Barth Syndrome Trust and CLIMB (The National Information and Advice Centre for Metabolic Disorders) to name a few.

She has also put effort into improving the newsletter – an important channel of communication not just with our members but with the wider world. For the first time we also had a stand at the British Society of

Human Genetics Annual Conference in York. This was a great opportunity to meet many of the geneticists, the counsellors and the scientists working across the UK, sharing information and telling them of our members concerns and (just as importantly) of their hopes.

### GIG's website - [www.gig.org.uk](http://www.gig.org.uk)

GIG's website has gone from strength to strength over the year. It regularly receives 20,000 or more visitors every month now, and it is an important source of information and comment for many people on genetic issues. A major development during the year occurred when our teaching pack "Genes and You" went on the website, with newly commissioned artwork some of which you can see in this annual report. In paper format this has been hugely successful with over 10,000 copies being distributed since it was first published, but now that it is available on the web it has a global reach.

Of course, our website does not exist in isolation. Through it, visitors can easily access a large number of other sites – not just of our members, but also those of a wide range of other organisations with whom we may share common concerns. One group of users who find the website particularly useful seem to be journalists and researchers from the media. They often consult it for background information on a wide range of topics, and this then frequently turns into a request for an interview or for further help in contacting people willing to be featured in an article or a programme.

### Artist in Residence

Telling people about genetics and about advances in our scientific understanding of genetic issues has been an important aspect of GIG's work for many years. However, just telling people is often not the best way of either convincing them that the issue is important or of making them remember the message once we have stopped talking.

For this reason we are always on the lookout for innovative ways of engaging with different audiences to get our message across. A few years ago we helped the Wellcome Trust when it commissioned a "theatre in education" play about genetics. We published materials for the brothers and



## Delivering the Message - Annual Report 2004 - 2005

sisters of those affected by genetic disorders at a time when no-one else was looking at their needs; and we have undertaken a number of other ventures to get our message across.

This year, thanks to generous support from Novartis, we have been able to appoint an "Artist in Residence". Sayward Morley, a fine arts graduate from Manchester Metropolitan University, with experience of working in the community, has been based at the North West Genetics Knowledge Park. She has been using the research and the health care expertise developed there as the inspiration for a series of workshops and other events for people of all ages and backgrounds from the community in the North West of England. This has not only introduced a large number of people to the world class research development and care that is being provided in that part of the UK; it has also produced some very original and inspirational pieces of art – encompassing not just the visual arts but music and the spoken word as well with genetics at the heart of this.

### Delivering to all

Following on from the work that Pritti Mehta undertook to develop a methodology for systematically assessing the extent to which access to genetic services were available to all sections of the community, we have been delighted to welcome Nick Meade to GIG. Nick, with funding from the Department of Health, has been carrying forward Pritti's work by establishing a number of "Beacon Projects" in partnership with NHS regional genetic centres. This will systematically monitor access to the services provided by these centres and ensure that they reach out equitably to all sections of the ethnically diverse community living in the area in which they operate. The first two beacon projects will be based in Liverpool at the Merseyside Genetic Service and in Exeter at the Devon and Cornwall Genetic Service.

Meanwhile, Pritti has continued to develop GIG's commitment to equity and equality through her work with the London IDEAS Genetic Knowledge Park. The initial brief for this work was to develop high quality genetic information accessible to families from non-English speaking environments in London and the South East. This was an important goal in itself, and work continues

towards achieving it – by the end of the project there will be leaflets, each addressing a particular aspect of genetics and health care available in up to twelve languages. This has been a truly collaborative effort. However, much more has come from this work – notably the development of a rigorous methodology for checking that translated information actually says what you think it does, in language and in terms that are comprehensible to the recipient, and also in the development of a standardised lexicon. This is important for interpreters and translators who may not fully understand the science that they are being asked to translate, and who otherwise may be forced to guess what a specific term (such as "chromosome" for example) might mean.

This work has implications far beyond genetics – it is hugely important across the whole of the NHS. This is being recognised by more and more people, and GIG's input in a variety of different contexts – including making a contribution to the development of quality standards for genetic services in the NHS, setting the framework for the Department of Health's HSR (Health Services Research) priorities, and the Antenatal and Neonatal Screening training programme to name but a few.

### Policy Matters

As research increases our knowledge of the links between our genes and our health or disease, so the implications of this for health care and for the well-being of our society come to the fore. New scientific opportunities create new requirements for regulation (or for the modification of old ways of doing things) if the positive advantages of new knowledge are to be realised for the benefit of those at risk, and unfair discrimination is to be avoided through preventing the misuse of genetic data.

GIG has been actively contributing to the policy debate and lobbying for changes in legislation (often in partnership with other groups) whenever there is a need.

Throughout the year GIG – usually through our Policy Officer, John Gillott – has been in extensive contact with senior figures in the Department of Health over the development of the Human Tissue Bill (now the Human Tissue Act). We also



## Delivering the Message - Annual Report 2004 - 2005

lobbied parliamentarians in both houses directly, making detailed proposals for changes to the provisions outlined in the Bill. In particular changes to ensure that analysis of tissue to benefit a relative was possible in a greater range of circumstances than originally proposed. Working closely with major research funding bodies such as The Wellcome Trust and the Association of Medical Research Charities, and with professional groups including the British Society for Human Genetics and the Academy of Medical Sciences, GIG helped to improve the drafting of this legislation. Progress was made in respect of both research and clinical issues and the legislation as finally enacted, although not perfect, was much improved on that originally proposed.

Also in the policy arena, GIG contributed to a wide range of consultations and other initiatives – including the enquiry by the House of Commons Science and Technology Committee into Human Reproductive Technology and the Law. This issue was also investigated by the Human Genetics Commission (HGC). GIG contributed to this formally, but it has also played a continuing role through the participation of GIG's Director as an (individual) member of the Commission. The HGC's report on this is due to be published in late 2005.

Other consultations and enquiries that we made an input to include the study by the HGC of the proposal to undertake broad spectrum genetic screening of babies at birth, consultations by the Human Fertilisation and Embryology Authority (HFEA) on the welfare of the child and other issues, and submissions to the Nuffield Council on Bioethics.

At a European level we also made an input to the revision of regulations concerning the conduct of clinical trials in children – an issue which will be very much a live one in 2005/2006! Whilst it sadly remains the case that many genetic diseases affect children, little is known about them, and we are a long way off developing effective treatments. Research is essential if prevention and cure are to become possible, but this must be carefully and appropriately regulated if we are to see the benefits, but without putting children at undue risk. The changes the European Union is proposing are driven by a desire to get the framework

right – but we must work to make sure that they do not stifle research by making it too difficult or too bureaucratic to do so efficiently, safely and quickly.

On a related issue, GIG has continued its work with Research Ethics Committees to help them to understand how genetic research works when dealing with rare disorders, so that the controls put in place to prevent exploitation of patients who might be vulnerable, are sensible and proportionate to the risks involved.

Of course genetic research is not just about rare diseases. The UK Biobank study continued to develop its plans during the year, with GIG contributing an in-depth analysis of communication and related policy issues to the planning process of this major study. We continue to have close links with the UK Biobank team and look forward to contributing to this project as it develops in 2005/2006.

The issue of so-called “late” abortions has caused some controversy during the year. GIG has contributed to the debate on this sensitive topic – highlighting the harms that would result to women if the upper time limit for abortion were to be cut back. Whilst we acknowledge that the issue of abortion arouses strong emotions, GIG's policy has always been that the choice is one that must be made by the woman (ideally with support from her partner and family). In the context of the ante-natal diagnosis of a genetic disorder artificial pressures resulting from an encroaching time limit will make the situation even worse than it already is.

### Quality Matters

When you are offered a genetic test you need to know that the information it might reveal is going to be useful, that you can rely on it to be accurate, and that it will be delivered in a way that is timely and appropriate. This is a problem that is not confined to the UK, so GIG was pleased to be invited to collaborate in an EU funded “Network of Excellence” called EuroGenTest. This aims to develop quality standards in genetic testing across Europe. Celine Lewis, started work in February 2005, is our Project Officer. She will be looking specifically at the information that is given to patients and families about genetic tests and developing standards for



## Delivering the Message - Annual Report 2004 - 2005

its comprehensibility and completeness. Although it is early days yet, it is already proving surprising just how little has been done in this area, so there is a real opportunity for GIG to make a difference here.

### Working with the Home Nations

Buddug Williams, GIG's Development Officer in Wales, is based in the Wales Gene Park. She has been working hard with colleagues in Welsh patient groups and in the professional community to map out the policy making and service development process in Wales, she has been identifying key players – clinicians, policy members and politicians (up to and including the Ministers and the Welsh Assembly Government). Service development mechanisms and the organisation of the NHS in Wales are taking an increasingly different course from the situation in England. It will become more than ever important that GIG is able to participate in the processes and procedures that evolve, so we can put our Welsh members' perspective on the issues as they arise. With a grant from the Wellcome Trust, Technquest and the Wales Gene Park, in conjunction with the University of Glamorgan and WIHSC (The Welsh Institute for Health and Social Care), conducted a Citizen's Jury with young people aged between 16-19 across Wales, on the topic of 'Genetics and Reproductive Decision Making' in Cardiff in September. Tom Barclay, our Assistant Director, was a member of the Steering Committee helping to prepare the event.

The majority of the jury was in favour of people being allowed to 'design babies' to prevent genetic conditions from being passed on and that it is acceptable to design babies for the purpose of curing existing children with serious medical conditions, so called 'saviour siblings'. However, the jury opposed the idea of designing babies for no medical reason, such as sex selection, and came down strongly in favour of regulation.

The Jury's recommendations were disseminated widely to key advisory and regulatory bodies, such as the Human Genetics Commission (HGC) and the Human Fertilisation and Embryology Authority (HFEA), as well as to schools, science centres, young people's organisations and others.



Scotland has a very different way of planning and organising its health care system from the model in England as well so we were delighted to learn that, in the 2005/2006 financial year, we are to receive funding from the Scottish Executive to enable us to appoint a part-time development officer in Scotland too.

### Educating the Professionals

The genetics white paper (Our Inheritance, Our Future) proposed setting up an education and training centre for NHS professionals who are not expert geneticists. Given recent advances, it will be increasingly important for all health care professionals to understand how genetic knowledge will have an impact on their day to day professional practice. The contract to develop this centre was awarded to Professor Peter Farndon's team in Birmingham. Anna Lane, GIG's Patient and Public Involvement Officer, is a key member of this team. Anna has been working on a review of patient perceptions of the clinical genetics out-patient service in the Midlands, and also on the educational needs of patients with a genetic predisposition to cancer. She has been in close contact with specialist commissioners in the region too – so that those who allocate the resources to pay for genetic medicine appreciate what it is that patients and families want and need and can understand the issues raised for them – in order to make better, more informed decisions as a result!

### GIG and Friends

Without active partnership with other "interested parties" GIG cannot be as effective as it should be – or as our members demand of us. Earlier in this report are comments on the active collaboration and engagement with our members that we have developed during the year. Partnership with other agents is also important. The Genetics Knowledge Parks have an important role to play in engaging and communicating information about genetics to the wider public in the different regions. They have people responsible for this aspect of their work, and Tom Barclay, our Assistant Director has been active in helping to create and support a network of people engaged in this that collaborates to create synergy and reach the widest

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possible audience effectively and efficiently. Tom has also played a role in a major European project known as SAFE (Special Non-Invasive Advances in Fetal and Neo-natal Evaluation Network) which is aiming to develop improved methods for detecting chromosomal abnormalities and so provide better opportunities for women to receive earlier and more accurate diagnosis where potential problems exist. GIG's input is on the communication / patient interest aspects of this project, not the basic science elements.

GIG's policy has always been to engage with anyone who is in a position to change things for the better for our members and the individuals and families they support. Throughout the year we have actively pursued this objective whenever and wherever we can – without ever compromising our independence or our ability to speak from the perspective of our members and those they represent.

To this end we have worked with the following during this year:

Association of British Insurers  
 Association of the British Pharmaceutical Industry  
 Bio Industry Association  
 British Society for Human Genetics  
 CESAGEN (Centre for Economic and Social Aspects of Genetics)  
 Department of Health  
 Department of Trade & Industry Human Genetics Commission  
 Economic and Social Research Council  
 EuropaBio (European Association of Bio Industries)  
 European Commission  
 European Federation of Pharmaceutical Industries & Associations  
 European Genetic Alliance Network  
 European Medicines Agency  
 European Parliament  
 Eurordis (European Rare Disorders Association)  
 Genetic Knowledge Parks  
 House of Commons  
 House of Lords  
 Human Fertilisation & Embryology Authority  
 INNOGEN (Centre for Social and Economic Research on Innovation in Genetics)  
 International HapMap Consortium  
 Joint Committee on Medical Genetics  
 Medical Research Council

National Institute for Clinical Excellence  
 National Institutes of Health (USA)  
 P3G Consortium  
 Wellcome Trust

& many more

### Press and Media

Most people learn about genetic issues through their newspapers or the television. GIG spokespeople have been extensively called on by journalists and the media for comments and briefings on a wide range of issues – some of which are controversial, such as the use of embryonic stem cells in research, whilst others are less so – explaining the implications or the possible benefits to be had from an advance in the treatment of a disease, for example. We have developed a close working relationship with the Science Media Centre, (<http://www.sciencemediacentre.org/>) and have participated in many of their briefings and other events, all of which aim to get accurate reporting of important scientific and medical developments in the arena of genetics and health into the press and on TV and radio. Often it is the human element that helps a journalist to see why a particular research outcome is important, and helps to translate it from something which might appear a bit “dry” into something which reaches people's hearts and minds, making it easier to appreciate the impact of genetic disease on families, and why GIG is so active in promoting the need for research and development and its application for the benefit of all our members.

### GIG Abroad

Genetics is an increasingly international activity. Mention has already been made of our engagement with European-wide initiatives – in terms of practical projects such as EuroGentest, and also at the level of policy and regulation. Orphan drug policy is a key area where some of our members have been able to benefit as new treatments come on to the market as a consequence of the initiatives and incentives provided by the Orphan Medicinal Products Regulations.

By the end of the year there were twenty licensed products and over 300 “orphan designations” recommended for approval, many of which will eventually turn into



## Delivering the Message - Annual Report 2004 - 2005

new treatments for rare diseases.

On a global level GIG has participated in the ethical, legal and social aspects of the International HapMap project. This is a multi-million pound project that is mapping genetic variations and similarities between populations, so that important disease and therapy-related occurrences can be mapped, and new interventions and products developed more effectively than at present. We have also worked with the Genetic Alliance, our sister organisation in the USA on issues relating to quality in genetic testing services, and to promote equity and fairness in access to services and support this will culminate in a conference to be organised in the USA in late 2005 on genetic testing issues.

### GIG Money

Although GIG's income in 2004/2005 was remarkably similar to the previous year; the surplus of £62,783 has turned into a deficit of £10,057. Two factors contribute significantly to this reversal, namely the need to make provision for partial repayment of an EU grant overpaid in previous years, and an increase in staff costs of £35,000 p.a. The first of these is a

one off, but the second is a recurrent cost pressure. Plans are in place to increase fundraising activity to meet these ongoing costs in future years.

GIG is grateful to all those who have demonstrated their support for our work through grants and donations. This commitment gives us the basis on which we can build and develop services and support for our members, and enables us to promote awareness of their needs and expectations for innovative and effective therapies and other forms of support.

Major Donors	Total 2005 (£)
Amersham International	2,000
Association of British Insurers	10,000
Association of the British Pharmaceutical Industry	5,000
Cambridge Genetics Knowledge Park	3,250
Department of Health (S64 Core Grant)	15,000
Department of health (S64 Project Grant)	23,250
Eurogentest	17,008
European Federation of Biotechnology	10,933
Friends Provident	5,000
GlaxoSmithKline	20,000
Golden Bottle Trust	1,000
HSA Charitable Trust	5,000
London IDEAS Genetic Knowledge Park	43,461
NHS (Research & Development Fund)	60,000
NOWGEN (The North West Genetics Knowledge Park)	10,000
Oxford Genetic Knowledge Park	10,250
Pfizer	10,000
SAFE	2,072
Wellcome Trust	37,472
Other Donations	4,786
<b>Total</b>	<b>295,482</b>

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<b>Extract of the audited Accounts for 2004/2005</b>		
Incoming Resources	Total Funds (2005)£	Total Funds (2004)£
Grants and Donations	295,482	297,655
Membership subscriptions	33,200	30,639
Investment income	12,966	8,594
Other incoming resources	210	1,250
<b>Total Incoming Resources</b>	<b>341,858</b>	<b>338,138</b>
<u>Resources Expended</u>	(£)	(£)
Cost of generating funds		
Fundraising and publicity costs.	14,023	9,036
<b>Net income Resources Available</b>	<b>327,835</b>	<b>329,102</b>
<b>Charitable Expenditure</b>		
Direct Charitable Expenditure	289,204	206,884
Management and Administration	48,688	45,587
<b>Total Charitable Expenditure</b>	<b>337,892</b>	<b>266,319</b>
<b>Total Resources expended</b>	<b>351,915</b>	<b>275,355</b>
<b>Net (expenditure)/income for the year.</b>	<b>(10,057)</b>	<b>62,783</b>
<b>Net movement in funds</b>		

### Statement on Funding

GIG is an independent charity. It accepts funding from a wide range of sources, public, private and voluntary. From time to time it will seek funding to undertake specific pieces of work or projects that, in the view of its Trustees, will further the achievement of the organisation's aims and purposes. GIG does not accept money that is conditional on it adopting or advocating policies or practices which are deemed not to be in the interests of its members. Nor does it accept funding from bodies where such acceptance would compromise its ability to pursue its long term goals and obligations

A copy of the complete accounts is available on request.

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### Trustees

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 Vicky Cowell (Vice Chair)  
 Chris Friend (Vice Chair)  
 John Gluckstein (Honorary Treasurer)  
 Dee Heaps (Honorary Secretary)

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 Professor John Dodge  
 Kit Farrow  
 Poly Gerondaes  
 Julie Greenfield  
 Fiona Hemsley  
 Anne Jolly  
 Patricia Morton  
 Dr Liz Nelson  
 Marilyn Park  
 Ann Philips

### Cooptees

Joanie Dimavicius  
 Ann Hunt (Resigned October 2004)

### Observers

Dr Hilary Burton  
 Professor Shirley Hodgson  
 Dr Tessa Homfray  
 Albert Njindou

### Advisors

Professor John Burn, MD, FRCP, FRCPCH, FRCOG  
 Professor Michael Connor, MD, DSc, FRCP  
 Professor Timothy Cox, MD, FRCP, FRCP (Glas), FMedSci, FRSE  
 Professor Kay Davis, CBE, MRCP (Hon), FMedSci, FRS  
 Dr Nick Dennis, MB, BChir, FRCP  
 Retired June 2005  
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 Professor Mike Patton, MA, MB, MSc, FRCP, FRCPCH  
 Professor Marcus Pembrey, MD, FMedSci, FRCP, FRCPCH, FRCOG

### Director

Alastair Kent

### The GIG Team

Thomas Barclay (Assistant Director)  
 John Gillott (Policy Officer)  
 Anna Lane (Development Officer)  
 Celine Lewis (Project Officer)  
 Nick Meade (Project Implementation Officer)  
 Pritti Mehta (Programme Manager)  
 Sayward Morley (Artist in Residence)  
 Helen Roden (Office Manager)  
 Lucy Ullmann (Fundraising Officer)  
 Buddug Williams (Wales/Cymru Development Officer)  
 Melissa Winter (External Communications and Membership Engagement Officer)

### 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)  
 The Arrhythmia Alliance



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Assert (the Angelman Syndrome Support Group)  
 Association for Glycogen Storage Disease (UK)  
 Association of Multiple Endocrine Neoplasia Disorders (AMEND)  
 Ataxia - Telangiectasia Society  
 Ataxia UK  
 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  
 DEBRA (National charity for Epidermolysis Bullosa EB)  
 Diabetes UK  
 Down's Heart Group  
 Dyskeratosis Congenita Society  
 East London Branch Sickle Cell Society  
 Ectodermal Dysplasia Society  
 Ehlers-Danlos Support Group  
 The Eyeless Trust  
 FAB UK (fanconi's Anaemia)  
 FAPGENE.CO.UK (familial Adenomatous Polyposis and Gardners Syndrome)  
 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 (the Craniofacial Support group)  
 Heart Haven  
 HITS (UK) Family Support Network  
 HME Support Group (Hereitary Multiple Exostoses 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  
 LOOK (National Federation of families with visually impaired children)  
 The Lowe Trust  
 Macmillan Cancer Relief  
 Manchester Sickle Cell and Thalassaemia Centre  
 The Max Appeal (Di George Syndrome, VCFS and 22q11.2 deletion)



## Delivering the Message - Annual Report 2004 - 2005

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  
 Pick's Disease 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  
 Rubenstein Taybi Support Group  
 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)  
 Tar Support Group

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

### Charity Number

**803424**

### Principal Address

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 London  
 N1 3QP

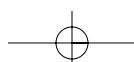
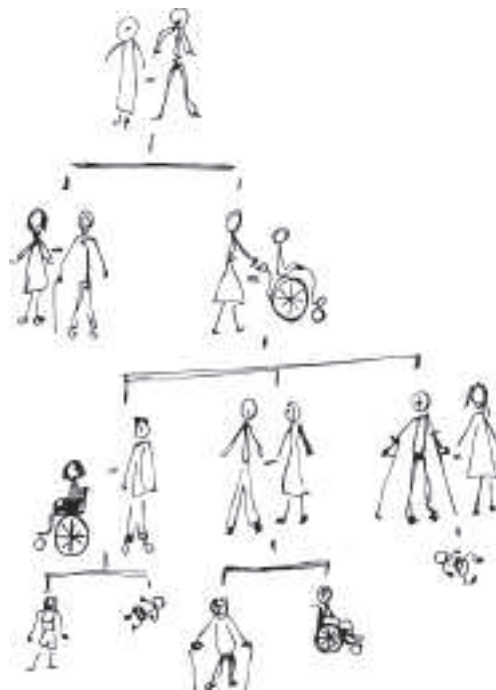
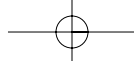
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