

Charity Registration No. 1114195 and SC039299

Company Registration No. 5772999 (England and Wales)

GENETIC INTEREST GROUP LIMITED

(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

REVISED TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31 MARCH 2009

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
LEGAL AND ADMINISTRATIVE INFORMATION

Trustees

Chris Friend (Chair)
Joanie Dimavicius (Vice Chair)
Chris Goard (Honorary Treasurer)
John Dart
John Dodge
Kit Farrow
Jane Fisher
Fiona Hemsley
Mike Knapton
Dr Liz Nelson
Marita Pohlschmidt
Ruth Sands
Elaine Miller (Co-opted)
Jerry Brown (Co-opted)
Maggie Ponder
Anne Jolly

Company Secretary

Mike Pearce

Observers

Dr Hilary Burton
Professor Shirley Hodgson
Dr Tessa Homfay

Director

Alastair Kent

The GIG Team

Celine Lewis (Eurogentest Project Officer)
Alex McKeown (Eurogentest Project Officer)
Nick Meade (Policy Officer)
Helen Parr (Fundraiser)
Gillian Scott (Development Officer Scotland)
Buddug Williams (Wales/Cymru Development Officer)
Melissa Hillier (Communications Manager)
Claire Cotterill (Patient Engagement Project Officer)
Benjamin Francis (Insurance Templates Project Officer)
Amy Hunter (Senior Research Officer)
Krystle Kontoh (Facilitating Networks Project Officer)
Heather Law (Office Administrator)

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
LEGAL AND ADMINISTRATIVE INFORMATION

Medical Advisers	Professor John Burn, MD, FRCP, FRCPCH, FRCOG Professor Michael Connor, MD, DSc, FRCP Professor Timothy Cox, MD, FRCP (Glas), FMedSci, FRSE Professor Kay Davies, CBE, MRCP (Hon), FMedSci, FRS Dr Roz A Eeles, MA, PhD, FRCP Professor Alan Emery, MD, PhD, DSc, FRCP, FLS, FRSE (Retired June 2009) Professor Peter Farndon, BSc, MD, FRCP, DCH Professor Nick Hastie, FRSE, FMedSci, FRS Professor Shirley Hodgson, DM, FRCP Professor Peter Lachmann, PMedSci, FRS Professor Norman Nevin, MD, FRCPE, FRCPath, FFCM (Belf) Professor Martin Richards, MA, PhD, ScD Professor Mike Ratton, MA, MB, MSc, FRCP, FRCPCH Professor Marcus Pembrey, MD, FMedSci, FRCP, FRCPCH, FRCOG
Charity number	1114195 and SC039299
Company number	5772999
Registered office	Unit 4D, Leroy House 436 Essex Road London N1 3QP
Auditors	Nyman Libson Paul Chartered Accountants Regina House 124 Finchley Road London NW3 5JS
Bankers	CAF Bank Limited 25 Kings Hill Avenue Kings Hill West Malling Kent ME19 4JQ

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
CONTENTS

	Page
Trustees' report	1 - 16
Statement of trustees' responsibilities	17
Independent auditors' report	18 - 19
Statement of financial activities	20
Balance sheet	21
Notes to the financial statements	22 - 27

**GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT
FOR THE YEAR ENDED 31 MARCH 2009**

The trustees present their report and financial statements for the year ended 31 March 2009.

The financial statements have been prepared in accordance with the accounting policies set out in note 1 to the financial statements and comply with the Charity's governing document, applicable law and the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005.

Trustees:

The Trustees who served during the year (unless otherwise stated) were:

Chris Friend (Chair)
Joanie Dimavicius (Vice Chair)
Chris Goard (Honorary Treasurer)
John Dart
John Dodge
Kit Farrow
Jane Fisher
Fiona Hemsley
Mike Knapton
Dr Liz Nelson
Dr Marita Pohlschmidt
Ruth Sands
Elaine Miller (Co-opted)
Jerry Brown (Co-opted)
Maggie Ponder
Anne Jolly

Observers:

Dr Hilary Burton
Professor Shirley Hodgson
Dr Tessa Homfay

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

Trustees are elected by the membership for a three year period. At the end of their period of office trustees retire. Retiring trustees may stand for re-election. Persons nominated for trusteeship must be proposed and seconded by the membership and provide a statement as to their work and experience which is distributed to the members prior to the ballot. This ensures that all trustees are familiar with and involved in the issues pertinent to the Genetic Interest Group (GIG).

New trustees receive individual induction from existing trustees and senior staff. New trustees are also provided with a comprehensive information package covering the organisation and work of the charity as well as information about the responsibilities of a trustee and potential conflicts of interest that may arise.

GIG's trustees have delegated management of GIG to the Director who reports to the trustees and is supported by 11 professional staff. The Director has responsibility for planning and the development strategies for GIG subject to policy guidelines determined by the trustees.

From time to time, GIG utilises the skills of volunteers recruited from either its membership groups or other stakeholders. These volunteers usually have the benefit of direct personal or professional experience of genetic disorders.

Furthermore, GIG has access to a network of contacts in both the lay and professional communities. These people provide advice, support and specific inputs to the activities of the organisation as and when the need arises.

Risk Management

The trustees have considered the major risks to which the charity is exposed and have established systems and procedures to manage and mitigate those risks. All risks faced are regularly reviewed at trustee meetings. Internal control risks are minimised by the implementation of procedures for authorisation of all transactions and projects.

Objects of the Charity

Genetic Interest Group Limited, a registered charity (number 1114195) company limited by guarantee (number 05772999) was incorporated on 16 April 2006.

Individuals and families affected by or at risk from disorders which arise from, or to which they may be at enhanced risk, as a result, of genetic changes need access to high quality health care which is based on accurate understanding of current scientific knowledge delivered in accordance with best clinical practice in a way that is timely and accessible.

For those at risk to be able to access such service, certain pre-requisite conditions must be met:

- There must be public awareness of the impact of genetics on human health and disease.
- There must be support for high quality biomedical research targeted at serious unmet medical needs.
- Services and support provided by the NHS and other agencies must be comprehensive, integrated and accessible.
- Unfair discrimination against those at genetic disadvantage must be combated.

GIG was created in order to achieve these objectives by creating an alliance, and umbrella group, that seeks to speak from the perspective of our 130+ member organisations and the individuals and families they support on issues of policy and strategy. GIG seeks to intervene strategically in issues of current concern in health care policy making, service provision and prioritization of public and private sector research, and the transfer of new knowledge arising from that research to product service and support for all those who need to benefit from them.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

Main objectives and goals for the year

In 2008/9 GIG sets a number of targets for the year. Some of these represented a continuation of ongoing themes from previous years, whilst some were new and would require the generation of additional resources not available at the beginning of the period.

a) Continuing Goals:

- to play a part in Department of Health and NHS policy and planning processes affecting development and provision of genetic service
- to inform the public, key opinion formers and policy makers of the views and opinions of our members
- to enhance the ability of service providers to reach all sections of society, thereby increasing equity and reducing social or cultural exclusion
- to boost the opportunity for families with very rare genetic conditions to receive comprehensive and integrated services and support from the NHS
- to facilitate the proper evaluation of the costs of genetic disease and the benefits arising from opportunities to intervene
- to build links with other groups in the UK, Europe and further afield to address issues of common concern likely to improve the opportunity for UK citizens to benefit from new services and therapies
- to provide support for those seeking to make the processes around research more efficient and patient friendly.
- to ensure that the ethical and social implications of large scale sample and data collections (BioBanks) reflect patient and family views and concern in their implementation.
- to input members' views on the use of animals in biomedical research.
- to develop innovative methods for communication with the general public about the impact of genetic diseases in families.
- to press for equitable and special access to innovative therapies.

b) New Goals:

- to develop mechanisms for the fair processing of sensitive medical information by insurers.
- to build on the links and the models created by the Family Route Maps Project in order to generate expert professional networks in the NHS.
- to work with the Department of Health and other stakeholders to develop a plan for integrated service provision for those with rare genetic disorders.
- to update and develop the GIG website.
- to produce a series of publications on 'current issues in genetics'.
- to campaign for the introduction of appropriate and proportionate regulatory mechanisms in the light of the enactment of the Human Fertilisation and Embryology Bill.
- to develop frameworks for enhancing patient participation in clinical trials and for understanding the medical implications of nanotechnology in biomedical research and development.
- to increase the breadth and diversity of GIG's funders and supporters through creative ethically robust PR and marketing strategies.

Strategies Used to Address Goals

GIG seeks to achieve its goals through the creation of strategic partnerships with other stakeholders, by undertaking novel projects relevant to our priorities and through the participation in the processes and procedures of other agencies. GIG seeks to present a well argued, realistic and rational perspective on current issues that reflects the needs and views of our members based on a democratically driven consultative process in which all members have an opportunity to participate.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

GIG seeks to understand the perspective of those with the power, the opportunity and the resources to change things for the better for our members and the families they support, and by positioning itself alongside this work with them to achieve change. Although GIG reserves the right to be confrontational should the need arise, its hope is to achieve influence through the development of mature relationships that can withstand disagreement whilst continuing to pursue areas of overlapping common interest.

GIG also seeks to improve the effectiveness of its members to argue for their specific interests and priorities by the provision of information, by imputing to their conferences, meetings and other activities, and through the opportunity for them to participate in research projects, consultations and public advocacy on their own behalf.

Chair's Introduction

Measuring the efficacy of an organisation such as the Genetic Interest Group is always difficult. Monetary and numerical factors used as yardsticks for many organisations are limited and most of our projects do not fit conveniently in to the parameters of the financial year. Because of this it is often necessary to assess our progress through identifying 'Tangible Achievements' - defined as 'positive things or events that would not have happened or occurred without the work of GIG'. During this year GIG provided its membership with a significant number of such achievements. These are all featured in this annual report and they demonstrate the broad scope of the GIG's work on behalf of patients and families whose lives are affected by genetic disorders. There are, however, two Tangible Achievements which deserve special mention.

The first is the significant part that GIG has played in ensuring that the Human Fertilisation and Embryology Bill became law without detriment to the progress of biomedical research and the welfare and prospects of our members and the patients and families they represent. Without strong campaigning from GIG there were dangers that pressure groups would have diverted the legislation away from its intended goals. Pre-Implementation Genetic Diagnosis, Saviour Siblings and Human-Animal Hybrid Embryos were the three main areas in which GIG worked with MPs and Ministers to ensure the needs of our members are met. Although the campaign was successful our work will have to go on to ensure appropriate implementation of the new law.

The second is the part GIG has played in establishing Rare Disease UK. This new organisation is a joint initiative of the Genetic Interest Group, (itself an alliance of over 130 charities supporting children, families and individuals affected by genetic disorders) and other key stakeholders including academics, doctors, healthcare planners and industry who seek an integrated programme of services and co-ordinated use of existing resources within the NHS. The aim is to get the Governments within the UK to support the EU Council Recommendation for creation of national strategies for rare diseases. Collectively rare diseases are not that rare! Some 1 in 17 people in the UK are affected by a rare disease. Currently there is no coherent strategy for integrated care and support for such people. Rare Diseases UK will strive to get such a programme implemented throughout the whole of the Country.

As to the future, the report reviews the ongoing projects which GIG is managing and provides information about new activities being undertaken through 2009 and 2010. These activities again demonstrate the important role that GIG fulfils in helping patients and families in areas where it is difficult for them to manage alone.

One major event to affect GIG this year has been Maggie Ponder's retirement from the post of Chair of the Trustees. In the six years that she has held the post Maggie's contribution has been immense.

In this time GIG has progressed significantly and has fulfilled the role its founders envisaged. Her standing in the fields of genetics and family care, together with her innate skills, have facilitated the establishment of a Trustee Board of exceptional scope and experience and an outstanding team of professional staff carrying out GIG's objectives and meeting its goals.

GENETIC INTEREST GROUP LIMITED

(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2009

The immense difficulties that children, parents and families are faced with in coping with rare and little understood disorders are hard for those not affected to understand whether they be health professionals, policy makers or 'just' members of the public. Obtaining a cohesive strategy within the NHS will be a big challenge but is one that GIG faces with enthusiasm and I believe, with the right policy and personnel. The right access to healthcare, the right to proper communication and the right information have been identified as key patient needs. They are particularly important in relation to all genetic disorders, rare or not so rare. These 'rights' GIG will continue to strive for.

Chris Friend
Chair of the Genetic Interest Group

What We Do

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

We campaign on key policy and political issues of the day and work on a wide range of issues at every level, from local to global. Our key activities include:

- Awareness raising
- Campaigning
- Giving patients a voice
- Influencing debates in genetics
- Influencing policy
- Providing information for patients
- Social research from the patient perspective
- Working with and supporting our members

1. Executive Summary

The benefits to GIG from winning the GSK/King's Fund "Impact" Award for 2008 continue to reverberate for us. The impact on our visibility and the creditability that this has given us has been significant. This is particularly true in respect of those who were unfamiliar with our work but who monitor developments in the voluntary sector. Hopefully it also acts as an indicator to funders (actual and potential) that we are a trustworthy and reliable organisation that will deliver on its promises and commitments effectively.

At the start of the year our Trustees and staff determined to use the opportunity that this award provided to best advantage by making sure that our systems were, as far as possible, fit for purpose and aligned with our strategic priorities. GIG is, and will remain a campaigning organisation that delivers strategic advocacy and targeted interventions in the key policy and political issues of the day. We do this from the perspective of our members, and of the patients and families who live with the daily impact of genetic diseases and disorders.

We work on a wide range of issues at every level from the local to the global, depending on where the levers that need to be pulled for the benefit of people with genetic conditions are situated.

**GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009**

2. Patients Influencing Policy

The start of the year covered by this report was busy with the passage of the Human Fertilization and Embryology Bill. This became law on the 13th of November 2008 and is in the process of having its provisions translated into regulations that will guide clinical practice and direct what researchers are allowed to do with human embryos and stem cells. The work on this is ongoing. GIG continues to work alongside scientists, clinicians, other patient groups and politicians to ensure that the Human Fertilization and Embryology Authority puts appropriate and proportionate regulation in place to interpret the provisions of the new Act.

The passing of this Act represents the end of a long policy campaign by GIG. When the Bill was first debated, in the House of Lords, alongside a group of scientists, clinicians, research groups and other patient organisations, we lobbied strongly for a number of changes in the wording of the Bill to reflect our support for ethically sound research on as many fronts as possible. Central to this raft of changes was a reversal in the Government's decision to ban the use of human-animal hybrid embryos, and important technology to speed up research into embryonic stem cells and their possible uses.

Once the Bill reflected our needs, we changed strategy, strongly supporting the Bill as it entered the House of Commons. Central to our communication strategy with MPs were a set of innovative "cartoons" which depicted the controversial processes, such as Preimplantation Genetic Diagnosis (PGD) and the creation of human-animal hybrid embryos, simply to aid MPs' understanding of the concepts.

Our sustained and resourceful campaign to shape the Human Fertilisation and Embryology (HFE) Bill and influence its progress through Parliament attracted significant interest amongst Parliamentarians, the media and the public and led to a dramatic shift in opinion on several controversial aspects of the Bill.

"Your support and invaluable input throughout this process was very much appreciated. It was instrumental in ensuring that the 2008 Act (.....) brings science and society in a way that is fit for the 21st Century." Rt Hon Dawn Primarolo, Minister of State in the Department of Health. (from June 2007 - June 2009)

Alongside this, GIG has been campaigning in Europe in particular on the issue of animals in medical research due to the revision of the EU Animal Welfare Directive 86/609/EEC. After a six year wait, the draft revision was published on the 5th of November. The idea behind this review is to strengthen and modernise EU law on the treatment of laboratory animals, bringing it into line with the best standards currently required in the EU, and to standardise the law across Europe. However, if the revisions are carried out without proper consideration of their impact, the continuing progress of the high quality biomedical research performed in the EU could be under threat.

GIG as a member of the European Genetic Alliances Network (EGAN) has been a vocal contributor to the debate, ensuring that patient's need for continuing high quality biomedical research is taken into account. The end of this year saw rapid progress in this review, resulting in the acceptance of the Agricultural Committees favourable revisions of the draft being accepted by the European Parliament. The process will continue through next year.

Alongside these campaigning initiatives, GIG continues to contribute our member's views to consultations and debates on issues ranging from education of doctors, to funding of expensive treatments in the NHS, genomic medicine and patients' rights.

GIG is also spear-heading a multi stakeholder consortium (Rare Diseases UK) to generate an integrated pattern of services and support for families with rare conditions. More about both of these features later in this report.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

3. Working in Collaboration

Sometimes life at GIG seems to be measured out in meetings and committees. Although this is sometimes be frustrating, the number of committees where we are asked to provide representation in an indication of the success of our strategy of adopting a co-operative rather than a combative approach to those with the power and resources to improve life for those affected by intractable conditions. Without relinquishing our rights and responsibilities we are able to challenge vigorously those whose actions or pronouncements threaten our members' interest, GIG believes in working alongside others in pursuant of shared goals.

With this in mind, the establishment of a new regulatory committee, the Committee of Advanced Therapies (CAT) at the European Medicines Evaluation Agency (EMA), was something we welcomed. This is the statutory committee that will play the major role in licensing new gene, stem cell and tissue therapies in Europe. It is good news that GIG's Director and Policy Analyst have been appointed members and alternate respectively on this committee. We will play a role in ensuring that the regulatory framework for these types of therapy (which hold significant promise of interventions for many of the conditions affecting GIG's members) is appropriate and proportionate to the risks and benefits involved.

GIG's Director was reappointed for a third term to the Human Genetics Commission (HGC), where a major focus this year has been the sale of genetic tests direct to consumers. This is usually via the internet, but a number of companies are offering DNA tests as part of a private medical consultation. GIG, and the HGC, have been concerned to strike the right balance. Direct to consumer tests can play an important role in enabling individuals access to information about their predisposition to common diseases. Some of those currently on offer base the claims they make on limited research, the outcomes of which may be insufficient to support the conclusions that are being drawn. People contemplating buying a DNA test need to be able to understand the limitations on any information that may be revealed, and whether they can trust it to act upon, in order to make an informed decision as to whether or not they want to purchase it.

In a rapidly changing field the scientific goalposts are constantly shifting, so the HGC is working on a Code of Practice for those who make and/or sell genetic tests direct to consumers. This will appear later in 2009, and its publication will, hopefully, help ensure that those purchasing tests from "code compliant" vendors can be reasonably confident in the accuracy and the validity of the service provided - GIG has played an active role in this work, contributing ideas and input to the drafts as they emerged and progress towards finalisation.

4. Working in the Devolved Nations

Health care policy is devolved to the UK's national governments, and we were delighted that our campaign to support the provision of services for families with inherited hyper cholesterolaemia (familial hypercholesterolaemia, FH) in Wales was crowned with success, while in Scotland our input to plans for children and young people's specialist services were well received.

Working in Wales

In Wales, GIG's campaign to improve health services for diagnosing inherited high cholesterol will make a real difference. GIG brought together families affected by FH with clinicians, scientists, and policy makers including the Wales Gene Park. Regular briefings and communications increased understanding, raised awareness of the condition and put the case for change and improvements to health services. Twenty-seven months into the campaign, the Welsh Assembly Government announced its commitment to fund a Wales-wide service to identify families at risk of this genetic condition through family cascade screening.

GENETIC INTEREST GROUP LIMITED

(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2009

Annual funding for this initiative of £650,000 has now been announced in a partnership between the Welsh Assembly Government and the British Heart Foundation. The programme will help find people in Wales at risk of this condition, diagnose them, and ensure people stay healthy and it will save lives. It is also anticipated that this will serve as a model to promote development of similar services to diagnose FH across England and Scotland, as well as for inherited cardiac conditions in Wales and beyond.

Work in other areas include improvements for neuroscience services in particular for neuromuscular conditions. GIG is an active member of the Wales Neurological Alliance, a successful collaboration between several organisations which has allowed smaller groups representing rarer conditions to contribute to policy development and contribute to the planning of future health services.

Scotland- Getting Patient Views Heard

Engagement

The Patient Engagement Project has been funded by the Scottish Government from April 2008. GIG in Scotland has been busy building links between individuals and groups affected by genetic conditions, and advocacy services such as the Scottish Patients Association. GIG has been recruiting to the GIG Scottish Consultative Virtual Patient Panel and currently has 50 members. The Panel are a sounding board for patient views about genetic developments in healthcare. The panellists regularly feed patient experience into Government and healthcare groups working to improve genetic healthcare in Scotland. GIG aim is to continue to expand the membership to include as many people as possible, with experience of a wide range of conditions, living throughout Scotland including the Borders, Highlands and Islands.

Policy work

A key element of GIG in Scotland's policy work was a consultation about the Scottish Government Patients' Rights Bill in December of 2008. To effectively canvas the views of Scottish people affected by genetic conditions, the GIG patient engagement network brought together the virtual panel and other GIG members and supporters with healthcare professionals, policy makers and researchers. The consultation was organised in conjunction with Gengage (the genetic healthcare public engagement network). A full day event investigated what rights and responsibilities patients, the government and NHS providers should have. Patients and carers who could not attend the day event, also fed in their views by email and by phone. The published report gives a far-reaching description of the needs and barriers that individuals and families with genetic conditions experience.

2009 has seen considerable GIG awareness raising activity in Scotland. GIG has been supporting the European Council's recommendation for action for Rare Diseases, identifying the need for the development of a National UK plan for Rare Disease. GIG members and virtual panellists successfully lobbied their MSPs and MPs and attended a successful launch of Rare Disease UK in the Scottish Parliament on the 3rd March.

GIG reported their consultation of parents' and professionals experiences of the cystic fibrosis (CF) newborn screening programme in Scotland. This focussed on the experiences when the baby's results were 'carrier' or atypical CF. The National Services Division of NHS Scotland are using this to help to mould their service more closely around patient needs.

Committee work

GIG in Scotland are active in numerous forums, informing the political and professional discussions about the services and resources needed to provide high quality genetic healthcare. GIG has been included on several Scottish Newborn Screening committee meetings developing policies and processes for MCADD, haemoglobinopathy and CF newborn screening. GIG has also helped to identify patients for these committees. Furthermore GIG has recently been invited to represent patients' interests in the commissioning of specialist services by National Services Division for NHS Scotland.

GENETIC INTEREST GROUP LIMITED

(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2009

GIG is also a member of the Scottish Molecular and Cytogenetic Genetics Consortium Users Group meetings, where we raise patient issues about tests as well as the Scottish Clinical Genetics Forum, contributing at regular meetings where clinical genetic service policies and practices are developed.

The 'Calman' Review of Genetics in Relation of Genetic Healthcare in Scotland is leading to improved genetic specialist staffing levels. It has also funded several demonstration projects aimed at providing more comprehensive care across traditional health and social care boundaries. These include Genetic Care Coordinator posts and GPs with a Special Interest in Genetics, who are each focussing on providing care coordination and multidisciplinary care for single gene disorders. Scotland-wide policies and practices in cardiac, neuromuscular genetic services, learning disability testing and genetic education are also developing at a pace.

GIG has recently joined as active members of the Scottish Cancer Coalition, and the Long Term Conditions Alliance Scotland. These are groupings of charities that are active in giving patient views and feedback on what is required in Scotland. We are of course contributing on behalf of those with genetic conditions.

5. Working at a European Level

Last year's annual report highlighted the fact that, rare diseases, when considered in a case by case basis, or condition basis are difficult for the NHS to take account of in a strategic manner. This is unfortunate, because rare diseases, taken as a whole affect over 3.5 million people in the UK, and are a cause of substantial suffering, consuming many millions of the NHS's budget. Unfortunately much of this expenditure is not well targeted. Families frequently rattle round the system, experiencing wasted consultations and unnecessary investigations as clinicians, keen to help but lacking the support, struggle to find a diagnosis. Even then, once a diagnosis has been revealed, families still find access to services and support more difficult than they need to be because of lack of coordinated planning and difficulties with the integration of different clinical inputs from across the NHS.

This is not a uniquely British problem. Fragmentation, difficulties in communication and a lack of data for evidence based medical decisions are a feature that hampers all European health care systems.

Rare diseases are one of the areas where the European Commission can play a clear role - adding value to the efforts of national health care systems. GIG has been a member of the European Commission's Rare Disease Task Force since its inception, and during the year our efforts were rewarded with the publication of a formal communication from the Commission "Communication from the Commission to the European Parliament, the Council, The European Economic and social committee and the committee of the regions on Rare Diseases; Europe's Challenges which called on Member States to develop National plans or strategies for integrated services and support to be provided to patients and families with rare diseases. The subsequent European Council's Recommendation on an Action in the field of Rare Diseases was adopted unanimously by the European Health Ministers.

Rising to the challenge, GIG has established Rare Disease UK (RDUK) a cross-sectoral alliance of patients, academics, doctors, healthcare planners and industry. RDUK will work with the Government, the Department of Health and the devolved nations to help secure a fair deal for families and individuals with rare diseases, with over 80% of rare conditions being genetic in origin we know this will have a positive impact on our members as well as a positive knock-on effect for genetic conditions that are considered more common. We believe that in the first instance much progress could be made by helping the NHS to work smarter - to spend the money it currently uses supporting patients with rare diseases to better affect. While we reserve the right to call for more investment in this area of health care, our first priority is to ensure that we secure the best health gain from resources currently being invested. Then there will be opportunity to push for more investment in research and development, and in the creation of new ways of working to address currently intractable diseases and disorders.

**GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009**

RDUK has been an initiative waiting to happen. It has received widespread support from all sectors, and it is clear that the time is right for this to happen. Of course the devil will be in the detail, and our task in the years to come will be to translate this willingness into a detailed plan that helps patients and families secure easy access to integrated services and where novel therapies are developed, to be confident that they will be able to access them if they are safe, effective and worthwhile.

6. Continuing GIG Projects

While policy development and its related campaigning activities are central to GIG's mission we must not underestimate the contribution that our project based work makes to achieving our goals.

Eurogentest and Eurogenguide, two major pan European projects promoting patient access to timely and user friendly genetic information and participation in research projects as active partners, not passive "subjects" continue to deliver solid progress.

EuroGenGuide

In July 2008 the EuroGenGuide website was launched the usage has remained very high with, on average, 20,000 hits per month. The website is viewed from all over the world, not just Europe and we have had usage as far afield as Mexico, Singapore and the United States as well as much of Europe.

The core material for EuroGenGuide was tested and assessed by the project team and members of their organisations during Autumn 2008 and improved according to their recommendations to generate version two of the material. This revised material was published online in January with enhanced core material and new features such as a forum, a mailing list and newsletter system, google translation, a tool providing automatic translation into over 40 languages. Further features will be added later in 2009. The current version of the Guide has been tested by a wide ranging patient user survey all over Europe. 74 patient groups have responded from 17 countries and their comments are being used to make improvements for the final version.

Dissemination of EuroGenGuide has been extremely important this year and the Project Officer has attended various meetings and conferences to support and promote EuroGenGuide, attending the First Eastern European Summit on pre-conception health, Budapest, European Genetic Alliances Network (EGAN) and Roche Annual Workshop, Basel, Central and Eastern European Genetics Network Conference, Prague, as well as making two presentations at the European Society of human Genetics Annual Conference.

EuroGentest

The original eleven patient information leaflets developed as part of the Eurogentest project have now been translated into over 26 languages and we are already in the process of translating an additional four leaflets that relate to the various genetic tests that are currently available through genetic clinics. These leaflets are all available on the Eurogentest website as PDF's to print out or as HTML pages to view online. Feedback about the leaflets has been very encouraging.

"Thank you very much for the Czech leaflets. It is very helpful for me". Geneticist, Czech Republic

"I received a brochure with information for patients on the topic of genetics, genetic counselling and testing, which is the most beautiful thank you". Alenka Vrežar, Slovenia

"I'm very glad to have so useful resource of professional information". Medical Geneticist, Russia

"Hello, this is really beautifully, and we will certainly use it in practice." Medical Geneticist, Croatia

**GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009**

Last month the leaflets and HTML pages were viewed over 8,000 times on the EuroGentest website, with almost 40% of all traffic on the website relating to the patient information pages.

This year one of the main aims has been to promote the availability of this information resource across Europe. This has been done through a number of channels. An article about the leaflets was recently published in the European Society Human Genetics Journal (March 09). In addition, GIG's Project Officer has attended numerous genetic conferences across Europe giving presentations about the leaflets as well as manning the EuroGentest stand where the leaflets in their many languages were on display. Conferences attended included the European Society meeting in Vienna, Austria; The Balkans Genetics Conference in Dubrovnik, Croatia; The Working Day for Human Genetics in Prague, Czech Republic; the Eastern European Rare Diseases Conference in Plovdiv, Bulgaria, and the MediMedGen conference in Ankara, Turkey. Access to the leaflets are now available through the European Society Human Genetics website, and clinicians across Europe are regularly updated about the availability of new leaflets in their language. As this project comes to a close (the project officially ends in December 2009) it is encouraging to know that we have successfully completed our original aim of developing good quality, user friendly information to patients across Europe, whatever country they are in.

7. New Projects

GIG has started three new projects in 2008/9 "Insurance Templates" and "Facilitating Networks" and "Patient Partner" each of which, when finished will make a contribution to ensuring a better deal for patients and families facing the impact of a genetic conditions. We are grateful to BUPA, the Department of Health and the European Commission respectively for the funding that makes this work possible.

Facilitating Networks Project

The first year of the Facilitating Networks project has been a success. Many of the objectives we planned to meet have been achieved; the most significant of these being the level of patient engagement harnessed within this formative stage.

Each of the project's nine patient support groups have been very accommodating in encouraging the patients and families they support to engage in the project's consultation process. Through the use of surveys (both online and postal), focus groups and attending support group meetings, the project's first year has been grounded in the individual and collective experiences of patients and families accessing much needed health and social care.

The information derived from the Family Route Map project produced a substantial body of evidence suggesting potential benefits of clinical networks for individuals affected by rare genetic conditions. Having received over 240 responses to the Facilitating Network's patient survey, the need for this project has been reaffirmed. The recurrent issues expressed by these individuals related to the experience of disjointed services, a general lack of communication amongst health professionals and insufficient awareness of their condition. These shared experiences generated a common ground for the support groups to levy the concerns of their members and created a synergy between grouped conditions which on some levels could have been perceived as disparate. Furthermore, the rich, earnest and relevant accounts of personal experiences strengthened the rationale for a networked approach to these problems.

The concerted effort to engage with clinicians and researchers who have knowledge and expertise of these conditions has been running alongside the patient consultations. The project employed a robust approach to identify individuals and organisations that could potentially feed into the efforts of the pending networks. Ensuring the patient support groups were at the centre of this communication was key, and in most instances the professionals who were already affiliated with the groups were approached first.

**GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009**

One to one interviews were conducted with professionals where they had the opportunity to volunteer their professional interests. Where clinicians were concerned, we placed an emphasis on their current, and previous experience of managing the patients with the conditions concerned. The need to map where individual and collective expertise would potentially contribute to the network's formation was at the core of all of the discussions held. Furthermore, the talks were vital in opening the dialogue to considering what areas of work the network could focus on. Through this process three clinicians emerged as trailblazers within their fields and have been identified as prospective champions for two of the networks.

The project has also been privy to advice from GIG members who have already taken a lead in developing clinical networks. These groups (PCD, Alstrom, CF Trust and DEBRA) were immensely supportive and open to sharing their respective journeys to achieving centres of excellence. This invaluable information will provide a framework for the imminent networks to evolve whilst following best practice and conserving limited time and resources.

Insurance Templates

GIG has continued its work with the Life Assurance Templates. These were previously developed in order to improve the application process for consumers, ensuring all of the relevant information is presented at the initial application stage. We are still working with the Association of British Insurers and various members of the Direct Office Underwriting Group to get these formally launched within the near future. It is important that Life Offices are briefed on the templates and their function within an underwriting process, in order for them to be fully integrated into applications.

GIG is committed to the concerns of our members and as part of our research it has become clear that Travel Insurance is continuing to present problems for many. GIG has been working towards creating an effective dialogue with the travel insurance industry in order to ensure positive patient outcomes. As part of this process it has been important for us to cultivate the views of as many GIG members as possible.

As such GIG developed an online survey which has been very successful and we would like to thank everyone who has taken the time to complete it. We now have well over 100 responses. Patient interviews and workshops with member groups has and will continue to provide further qualitative data which can be used to formulate themes and identify reoccurring problems in order for solutions to be developed. GIG will then be able to use this data by working closely with the industry and trade bodies to demonstrate the nature of the difficulty consumers living with pre-existing medical conditions experience when applying for insurance. As part of GIG's continuing support for our members we will be developing a handy leaflet to ensure people are fully informed about the insurance products they are buying and offer guidance to limit the risk of claims going unpaid.

Patient Partner

Patient Partner is a project which sets out to promote the role of patient organisations in the clinical trials context.

Patient Partner is based on the belief that involving patient organisations as equal partners at all stages of clinical trials contributes to research that is better adjusted to the real needs of patients. It is a three year project within the 7th framework programme funded by the European Commission. The study will take a close look at the part that patient organisations play and are willing to play in clinical trials and will mainly focus its attention on clinical trials with children, the use of biobanks and ethical issues. The Genetic Interest Group is leading on the dissemination work package for the Patient Partner Project.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

8. Leading the Patient Voice

In addition to these major pieces of work, GIG has played a role in a number of other projects coordinated and led by others.

One of the most worthwhile of these has been "Capability" (Capacity for the transfer of Genetic Knowledge into Practice and Prevention: An International Collaborative Network) where we have been working with European colleagues from Germany and Sweden, and partners in South Africa, Argentina and Egypt. GIG has contributed to creating pilot models for sustainable service development in genetics in the three partner countries. In Egypt this has generated educational materials for couples who have had little or no formal education and who cannot read to enable them to understand the idea of a genetic risk. In Argentina large numbers of primary health care professionals in a remote Northern province have been trained via a series of workshops and seminars, and in South Africa, midwives operating in the community far away from expert help have been given training and support to help identify newborn babies with genetic problems, to treat these appropriately and guide the parents to genetic counselling clinics operated in the District Hospital for that part of their country.

Case study from the Capability Project

If a mother gives birth to a child with a congenital abnormality away from the main centres of population in South Africa, the ante natal care will be provided by a midwife. The training of midwives is such that they often have little awareness of the need to diagnosis birth defects.. There is a risk that the babies may not receive appropriate treatments and there is also a risk that the parents could carry on to conceive another child with a similar condition, if it is genetic.

The Capability Project did a short awareness training programme and provided a group of midwives with a mobile phone that could take reasonably high quality pictures. The idea was that if a baby was born that the midwife felt may not be "normal" they were trained to ask a series of questions and to take specific photographs. The answers to the diagnostic questions and pictures are then sent by SMS to a dedicated number at the clinical genetics laboratory in Johannesburg. There a clinical geneticist could make an informed attempt at diagnosis and call the midwife back to discuss the appropriate course of action. The first time this was used in practice was for a case of Trisomy 18, a devastating and lethal condition. The geneticist was able to advise palliative care and counselling for the parents, this meant that at the rural hospital one of their two valuable ambulances was not tied up for more than a day transporting the baby to the nearest tertiary centre, who would have been unable to do anything further for the baby.

As you can see from the case study the pilots are already paying dividends in health care terms, demonstrating that even a small amount of additional resources, used properly, can make a substantial difference to the lives of children, couples and families at risk.

The UK is at the forefront of developments within clinical genetic services and this project has enabled GIG to share the UKs good practices to those affected by genetic conditions in the developing world.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

Another project, closer to home this time, involves the NHS in the North West, the University of Manchester and GIG. The Project "Genetics for Patients" is being undertaken by Dr Marion McAllister. The project aims to develop a new measure of outcome for clinical genetics services. This patient questionnaire could make it possible to evaluate different ways of providing those services, to ensure they were developed to meet patient needs. Because there are often no medicines or operations to offer, it has been difficult to find ways to measure the patient benefits, and services have developed without good research evidence. This project builds on previous research which identified "empowerment" as the primary patient benefit. GIG has helped in recruiting patients to complete the specially designed questionnaire, in order to validate it before it is given to patients before and after attending a clinical genetics service. This validation will be useful in helping to develop services to better meet the needs of the families it serves.

Funding from the Scottish Government enabled us to appoint a full time Patient Engagement Officer based alongside our Development Officer in the Genomics Forum (part of the University of Edinburgh) she has been building networks of patients and carers interested in supporting the improvement of genetic services in Scotland. Following the Calman Review £10 million of new money is to be invested in modernising the genetic service in the NHS Scotland. With GIG's help these developments will be user friendly and relevant to patient and family needs. Funding from the Calman Review enabled GIG to appoint a full time patient engagement officer in Scotland, patient and families able to comment on and contribute to the development of NHS services and other health and research related issues.

Also in Scotland, our Development Officer completed a survey of families taking part in the newborn screening programme for Cystic Fibrosis. The findings from this highlighted training and communication gaps that will need to be addressed for this programme to ensure that parents are well informed and willing to participate.

9. Funding

In reviewing the year it is impossible to avoid recognising the growing danger to our activities and, more importantly to the hopes and expectations of the families supported by all our member groups that the "credit crunch" poses. As the long term cost of measures taken to bail out banks and industries begin to hit home, it is clear that GIG, and all its members, face an uncertain future. Generating resources to support our core activities of policy and campaigning has always been challenging and it is likely to become more so. We will need to work hard to cement relationships with our existing funders and to develop awareness of our work amongst new audiences and potential supporters.

Notwithstanding these difficulties, we enter the new financial year optimistically. We have secured funding for our role in a new European Project - Patient Partner. We will be involved in a five year programme funded by the National Institute for Health Research (the NHS's Research and Development arm) called "Reliable, Accurate, Prenatal Non Invasive Diagnosis (RAPID) to manage the introduction of non-invasive pre natal diagnosis (checking the development of the fetus by testing DNA in the mother's blood) into clinical practice. We have also secured funding from the Big Lottery Fund Research Programme for a new three-year research project. The Family Risks, Common Cancers and People from Minority Ethnic Groups project will be led by GIG in partnership with the Division of Primary Care at the University of Nottingham. The project will identify why people from minority ethnic groups with a significant family history of cancer are less likely to access genetics services than the mainstream UK population and will inform the development of interventions to improve access to these groups.

During the last year we have managed to strengthen our relationships with many of our existing funders and two of our existing core grants are to be renewed for a further term. Our concerted effort to engage with new corporate sponsors has also had some success and we have attracted both cash and in-kind donations from several new sources. We will be working hard to develop these relationships in the long term.

GENETIC INTEREST GROUP LIMITED

(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE CAPITAL)

TRUSTEES' REPORT (CONTINUED)

FOR THE YEAR ENDED 31 MARCH 2009

2008/09 has been a year in which we have explored new fundraising approaches. In September, we became the first charity partner of the on-line shopping club, KidStart. By using the KidStart website, shoppers can earn savings from over 200 well-known retailers, which they can then transfer to a child's trust fund, a school or one of the five charities listed on the website, including GIG. In February we were selected as one of a group of charities to be supported by the St George's University of London RAG Week and we will receive £4,000 raised through a variety of student charity events. As well as generating income, both these activities have the additional advantage of raising GIG's profile amongst new audiences.

So while the future is challenging, it is not all doom and gloom. We are confident that we are well placed to ride out the worst effects of the credit crunch by exercising due caution in managing our assets, developing our relationships with our allies and exploring new opportunities as they arise.

The Year Ahead

We enter the new financial year optimistically with a number of new projects in the pipeline.

RAPID: GIG will be involved in a five -year programme funded by the National Institute for Health Research, the NHS's Research and Development arm. The Reliable, Accurate, Prenatal Non -Invasive Diagnosis (RAPID) project will manage the introduction into clinical practice of non -invasive prenatal diagnosis, which involves checking the development of the foetus by testing DNA in the mother's blood.

Family Risks, Common Cancers and People from Minority Ethnic Groups: This new three-year research project, funded by the Big Lottery Fund Research Programme, will be led by GIG in partnership with the Division of Primary Care at the University of Nottingham. The project will identify why people from minority ethnic groups with a significant family history of cancer are less likely to access genetics services than the mainstream UK population and will inform the development of interventions to improve access to these groups.

Treasurer's Report

There is no doubt that 2008/9 was a difficult year - particularly for the economy but also for GIG. It was the first year of our new company status, intended to provide greater security for the charity & its Trustees and timely too given the wavering banks, currencies and charity income.

Data from the Charities Commission shows that organisations of our size have found it much more difficult to grow revenue in real terms than the very large charities who have been able to continue to persuade consumers to continue to give. Income for GIG however comes from two main sources, the major donors who have contributed rather less to us this year although there is a timing issue that suggests donations are flat rather than declining. The second source includes the various organisations who commission us to produce reports on their behalf. This latter group has shown considerable growth, unfortunately not enough to fill the gap created by declining Grants but welcome just the same. In such a challenging environment our fundraiser Helen Par deserves praise for her commitment, persistence and unstinting efforts

Our deficit this year is 5.2% of income and at £30k is the lowest for the last three years. We believe if concentrate on managing costs we can aim to achieve break even in our new financial year.

We have adequate reserves to continue and the determination to focus on our new campaign activities. Moving into our new financial year we are actively reviewing our financial strategy to improve our cost management and refine our Project activities. It will be essential to ensure we manage our financial responsibilities with great care and initial forecasts are looking more positive.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
TRUSTEES' REPORT (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

Review of Financial Position

Income for 2008/09 increased by 22% over 2007/08 levels (2008/09 - £574,017, 2007/08 - £469,156). The reason for this increase was entirely due to the receipt of additional grants to fund specific projects (restricted funds). Grant income for specific projects rose by 48% (£440,305 compared to £296,869 for the previous year). Unfortunately unrestricted income went down from £172,287 last year to £133,712 for 2008/09. Grant income now accounts for 77% of total revenues (up from 67% last year). Donations comprise approximately 14% and subscriptions from members comprise 7%.

Expenditure for the year was £604,063 (2007/08 - £511,307) resulting in a deficit for the year of £30,046. The costs of running the charity dropped by nearly £10,000 over last year; hence allowing a significant increase in expenditure devoted to charitable activities and total expenditure on charitable activities rose from £420,464 last year to £529,657 for 2008/09. This sum represents 88% of GIG's total expenditure (2007/2008 - 82%).

Reserves Policy

The charity has free reserves of £129,134 which represents over 9 months of unrestricted fund expenditure on all activities. In the event of a future shortfall in funds raised the charity needs to hold minimum reserves of £67,000 to cover the costs of closing the organisation down. This figure represents the current estimate that would be required to pay the staff who would be redundant and other commitments which would need to be met.

The trustees therefore consider that the reserves held are sufficient to meet current and ongoing needs.

Disclosure of information to auditors

Each of the directors has confirmed that there is no information of which they are aware which is relevant to the audit, but of which the auditor is unaware. They have further confirmed that they have taken appropriate steps to identify such relevant information and to establish that the auditors are aware of such information.

Auditors

In accordance with section 485 of the Companies Act 2006, a resolution proposing that Nyman Libson Paul be reappointed as auditors of the company will be put to the Annual General Meeting.

On behalf of the board of trustees

Chris Friend
Chair of Trustees

Chris Goard
Honorary Treasurer

Dated: 14 December 2009

**GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
STATEMENT OF TRUSTEES' RESPONSIBILITIES**

The trustees are responsible for preparing the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of its incoming resources and application of resources, including its net income and expenditure for the year.

In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and estimates that are reasonable and prudent; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and which enable them to ensure that the financial statements comply with the Companies Act 1985. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF GENETIC INTEREST GROUP LIMITED

We have audited the financial statements of Genetic Interest Group Limited for the year ended 31 March 2009 set out on pages 20 to 27. These financial statements have been prepared in accordance with the accounting policies set out on page 22.

This report is made solely to the charitable company's members, as a body, in accordance with Section 235 of the Companies Act 1985. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and its trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of trustees and auditors

As described on page 17, the trustees, who are also the directors of Genetic Interest Group Limited for the purpose of company law, are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Our responsibility is to audit the financial statements in accordance with relevant legal and regulatory requirements and International Standards on Auditing (UK and Ireland).

We report to you our opinion as to whether the financial statements give a true and fair view and are properly prepared in accordance with the Companies Act 1985. We also report to you whether in our opinion the information given in the Trustees' Report is consistent with the financial statements.

In addition we report to you if, in our opinion, the charity has not kept proper accounting records, if we have not received all the information and explanations we require for our audit, or if information specified by law regarding trustees' remuneration and transactions with the trustees is not disclosed.

We read the Trustees' Report and consider the implications for our report if we become aware of any apparent misstatements within it.

Basis of opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the trustees in the preparation of the financial statements, and of whether the accounting policies are appropriate to the charitable company's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion we also evaluated the overall adequacy of the presentation of information in the financial statements.

**GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
INDEPENDENT AUDITORS' REPORT (CONTINUED)
TO THE TRUSTEES OF GENETIC INTEREST GROUP LIMITED**

Opinion

In our opinion the financial statements:

- the financial statements give a true and fair view in accordance with United Kingdom Generally Accepted Accounting Practice of the state of the charity's affairs as at 31 March 2009 and of its incoming resources and application of resources in the year then ended; and
- the financial statements have been properly prepared in accordance with the Companies Act 1985; and
- the information given in the Trustees' Report is consistent with the financial statements.

Nyman Libson Paul

Chartered Accountants
& Registered Auditors

Dated: 14 December 2009

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 MARCH 2009

	Notes	Unrestricted funds £	Restricted funds £	Total 2009 £	Total 2008 £
<u>INCOMING RESOURCES</u>					
<u>Incoming resources from generated funds:</u>					
Voluntary income					
Transfer from unincorporated charity		-	-	-	216,804
Donations	2	81,237	-	81,237	101,175
Grants	2	-	-	-	16,666
Activities for generating funds					
Membership subscriptions	3	39,470	-	39,470	35,071
Investment income	4	12,702	-	12,702	18,921
<u>Incoming resources from charitable activities:</u>					
Grants receivable	5	-	440,305	440,305	296,869
Other incoming resources		303	-	303	454
Total incoming resources		133,712	440,305	574,017	685,960
<u>RESOURCES EXPENDED</u>					
Costs of generating funds					
Costs of generating voluntary income		24,991	-	24,991	31,676
Charitable activities		97,157	432,500	529,657	420,464
Governance costs		49,415	-	49,415	59,167
Total resources expended	6	171,563	432,500	604,063	511,307
Net movement in funds		(37,851)	7,805	(30,046)	174,653
<u>RECONCILIATION OF FUNDS</u>					
Fund balances at 1 April 2008		166,985	7,668	174,653	-
Fund balances at 31 March 2009		129,134	15,473	144,607	174,653

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
BALANCE SHEET
AS AT 31 MARCH 2009

	Notes	2009 £	£	2008 £	£
Current assets					
Debtors	9	103,213		32,963	
Cash at bank and in hand		286,833		340,294	
		<u>390,046</u>		<u>373,257</u>	
Creditors: amounts falling due within one year	10	<u>(245,439)</u>		<u>(198,604)</u>	
Total assets less current liabilities			<u>144,607</u>		<u>174,653</u>
Income funds					
Restricted funds	11		15,473		7,668
Unrestricted funds			<u>129,134</u>		<u>166,985</u>
			<u>144,607</u>		<u>174,653</u>

The financial statements were approved by the Board on 14 December 2009 and signed on its behalf by:

Chris Friend - Chair of Trustees

Chris Goard - Honorary Treasurer

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

1 Accounting Policies

(continued)

1.6 Fund accounting

Restricted funds are accounted for in accordance with the particular terms of trust arising from the express or implied wishes of donors and grant making bodies in so far as these are binding on the trustees.

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objects of the charity.

1.7 Taxation

The charity is a registered charity and is exempt from income tax and corporation tax under S505(1) of the Income and Corporation Taxes Act 1988.

2 Donations and grants

	Unrestricted funds £	Restricted funds £	Total 2009 £	Total 2008 £
Donations				
Association of The British Pharmaceutical Industry	9,000	-	9,000	8,000
BBC Appeal - St James Palace Foundation	-	-	-	1,000
Bourne End & Cookham Rotary Club	1,250	-	1,250	-
Cardiff University	-	-	-	2,000
Genzyme	10,000	-	10,000	5,000
GE Healthcare	2,000	-	2,000	2,000
Glaxo SmithKline IMPACT Award	25,000	-	25,000	40,000
Golden Bottle Trust	-	-	-	1,000
Medical Research Council	16,000	-	16,000	16,000
Merck, Sharp & Dohme Limited	1,000	-	1,000	10,000
National Services Division	-	-	-	5,100
Novartis	-	-	-	4,345
Roche	10,000	-	10,000	-
Other donations	6,987	-	6,987	6,730
	<u>81,237</u>	<u>-</u>	<u>81,237</u>	<u>101,175</u>
Grants				
Wellcome Trust	-	-	-	16,666
	<u>-</u>	<u>-</u>	<u>-</u>	<u>16,666</u>

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

3 Activities for generating funds

	2009 £	2008 £
Membership subscriptions	<u>39,470</u>	<u>35,071</u>

4 Investment income

	2009 £	2008 £
Interest receivable	<u>12,702</u>	<u>18,921</u>

5 Grants receivable

	Unrestricted funds £	Restricted funds £	Total 2009 £	Total 2008 £
Scottish Executive	-	23,420	23,420	21,115
Scottish Government	-	41,800	41,800	-
Sixth Framework Programme (Eurogentest)	-	78,563	78,563	106,026
Sixth Framework Programme (Eurogenguide)	-	119,488	119,488	110,000
Sixth Framework Programme (Capability)	-	16,561	16,561	2,662
SAFE	-	19,346	19,346	2,347
BUPA Giving	-	56,403	56,403	-
Department of Health, Section 64	-	32,788	32,788	-
Association of British Pharmaceutical Industries (ABPI)	-	28,717	28,717	-
Seventh Framework Programme, EU (Patient Partner)	-	13,424	13,424	-
The Big Lottery Fund	-	9,795	9,795	-
Jeans for Genes	-	-	-	17,125
Department of Health S64 Project Grant	-	-	-	7,750
London IDEAS Genetic Knowledge Park	-	-	-	24,844
NOWGEN (The North West Genetic Knowledge Park)	-	-	-	5,000
	<u>-</u>	<u>440,305</u>	<u>440,305</u>	<u>296,869</u>

6 Total resources expended

Total resources expended, comprising costs of generating funds, expenditure on charitable activities and governance costs, including the reallocation of support costs, is fully analysed in the detailed Appendix attached. This appendix forms part of the audited financial statements.

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

7 Trustees

None of the trustees (or any persons connected with them) received any remuneration during the year. Trustees were reimbursed a total of £756 (2008: £122) in respect of travelling expenses.

8 Employees

Number of employees

The average monthly number of employees during the year was:

	2009	2008
	Number	Number
	12	11
	<hr/>	<hr/>
Wages and salaries	285,613	260,983
Social security costs	28,918	26,563
Other pension costs	9,317	14,926
	<hr/>	<hr/>
	323,848	302,472
	<hr/>	<hr/>

No employee earned more than £60,000 per annum (2008: Nil).

The charity does not operate a pension scheme for its employees but does administer contributions to a personal pension scheme of each staff member's choice. The charity contributes 7% of salary providing the employee contributes a minimum of 3%. During the year to 31 March 2009 the charity made contributions in respect of 7 employees (2008: 9)

9 Debtors

	2009	2008
	£	£
Other debtors	99,301	29,051
Prepayments and deposits	3,912	3,912
	<hr/>	<hr/>
	103,213	32,963
	<hr/>	<hr/>

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

10 Creditors: amounts falling due within one year	2009	2008
	£	£
Trade creditors	2,414	4,313
Other creditors	127,436	65,220
Accruals	4,231	3,231
Deferred income	111,358	125,840
	<u>245,439</u>	<u>198,604</u>

11 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants held on trust for specific purposes:

	Movement in funds			
	Balance at	Incoming	Resources	Balance at 31
	1 April 2008	resources	expended	March 2009
	£	£	£	£
Scottish Office	38	23,420	(23,158)	300
Patient Engagement	-	41,800	(39,227)	2,573
Eurogentest	8,384	78,563	(76,103)	10,844
Eurogenguide	(1,932)	119,488	(127,281)	(9,725)
Capability	-	16,561	(16,561)	-
SAFE	1,178	19,346	(20,042)	482
Insurance Templates	-	56,403	(53,030)	3,373
Facilitating Networks	-	32,788	(28,918)	3,870
RDUK	-	28,717	(27,386)	1,331
Patient Partner	-	13,424	(11,355)	2,069
The Big Lottery Fund	-	9,795	(9,439)	356
	<u>7,668</u>	<u>440,305</u>	<u>(432,500)</u>	<u>15,473</u>

12 Analysis of net assets between funds

	Unrestricted	Restricted	Total
	funds	funds	
	£	£	£
Fund balances at 31 March 2009 are represented by:			
Current assets	148,124	241,922	390,046
Creditors: amounts falling due within one year	(18,990)	(226,449)	(245,439)
	<u>129,134</u>	<u>15,473</u>	<u>144,607</u>

GENETIC INTEREST GROUP LIMITED
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING A SHARE
CAPITAL)
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 MARCH 2009

13 Commitments under operating leases

At 31 March 2009 the company had annual commitments under non-cancellable operating leases as follows:

	2009	2008
	£	£
Expiry date:		
Between two and five years	3,055	3,055
	<u> </u>	<u> </u>

14 Related parties

During the year the company received funds totalling £nil (2008: £216,804) from The Genetic Interest Group, an unincorporated registered charity with a Board of Trustees in common.

THE GENETIC INTEREST GROUP

Notes to the accounts (continued)

For the year ended 31 March 2009

6. Total Resources Expended

	Basis of allocation	Memberships and Fundraising	Advice Information and Education	Scotland	Patient Engagement	Eurogen test	Eurogen Guide	Capability	SAFE	Insurance Templates	Facilitating networks	RDUK	Patient Partner	Big Lottery	Governance	2009	2008
Costs directly allocated to activities																	
Specific Project Work	Direct			-	-	-	74,468	-	-	-	-	-	-	-		74,468	71,730
Direct charitable expenditure - Staff costs	Direct			17,418	29,541	31,381	26,918	-	4,150	29,076	17,975	7,216	-	-		163,675	127,634
Consultancy	Direct	1,200	-	-	-	14,785	4,654	-	-	15,375	-	-	-	-		36,014	21,324
Travel & Accomodation Expenses	Direct			1,313	2,131	6,787	4,737	5,862	1,716	450	962	414	109	-		24,481	23,310
Other Directly attributable costs	Direct			1,345	820	5,519	10,013	7,721	1,609	600	767	13,340	52	7,363		49,149	16,283
Website			13,326													13,326	3,496
Subscriptions			7,938													7,938	1,046
Audit Fee	Direct			-	-	-	-	-	-	-	-	-	-	-	3,995	3,995	3,230
Depreciation																-	-
Support costs allocated to activities																	
Staff Costs	Staff time	21,952	46,530	2,971	6,735	11,885	1,585	1,585	11,156	2,377	5,942	3,962	7,923	1,585	36,027	162,215	180,431
Occupancy Costs	Head Count	488	5,650	-	-	2,439	2,439	610	610	2,561	1,626	1,220	1,626	244	2,438	21,951	21,062
Meeting rooms and conferences	Head Count	169	1,957	-	-	845	845	211	211	887	563	422	563	84	844	7,601	8,234
Travel and subsistence	Allocation		4,289													476	8,866
Printing telephone and stationery	Usage		13,708	112		839		167	185							376	13,432
Legal and professional fees	Allocation	857														3,638	2,596
Office equipment and maintenance	Head Count	297	3,440	-	-	1,485	1,485	371	371	1,559	990	743	990	149	1,485	13,365	7,171
Other management and administration costs	Head Count	28	319	-	-	138	138	34	34	144	92	69	92	14	136	1,238	1,462
Total Resources expended		24,991	97,157	23,159	39,227	76,103	127,282	16,561	20,042	53,029	28,917	27,386	11,355	9,439	49,415	604,063	511,307