Genetic Alliance UK
Supporting. Campaigning. Uniting.

Annual Report and Accounts

2012 – 2013

Welcome to our Annual Report and Accounts

for 1 April 2012 – 31 March 2013

We have written this year's report to be as accessible to as many people as possible. In the first half of the report, we have included an overview of our achievements in this year and our plans for the future. In the second half of the report is the trustees' report, our financial statements and accounts for the year.

Contents

About us

Genetic Alliance UK is the national charity of over 160 patient organisations supporting all those affected by genetic conditions. Our aim is to improve the lives of people affected by genetic conditions, ensuring that high quality services and information are available to all who need them.

What we do

Supporting: We seek to raise awareness of genetic conditions and improve the quality of services and information available to patients and families.

Campaigning: We actively campaign on behalf of those with genetic conditions on issues of policy and practice to influence governments, policy makers, industry and care providers such as the NHS.

Uniting: We provide a united voice for all those affected by genetic conditions, enabling us to work together towards the common goal of making life better for patients and families at risk.

We are the only organisation in the UK that provides a voice for all patients and families affected by genetic conditions on a European, UK and devolved nation level.

About genetic conditions

Genetic conditions are life-long and serious illnesses, affecting multiple systems of the body. Many are progressive, meaning affected individuals lose their health, quality of life and may die prematurely. Currently, few genetic conditions can be cured, and few have effective treatments; but all individuals and their families need appropriate care and support, as well as timely and accurate diagnosis. Patients and families with genetic conditions often have a high level of unmet need.

It is vital that medical research sheds light on these conditions in order to develop effective interventions and therapies and that they are made available to patients as soon as possible, with appropriate care and support, to improve health and save lives.

There are over

6,000

different genetic conditions

4 out of every

100 BABIES

born in the UK have a genetic condition

6 out of 10 PEOPLE

are likely to develop a disease that is partially genetically determined by the age of 60

Letter from the Chair and the Director

2012 – 2013 has been a very busy year for us, and we are proud of our work and our achievements.

We are particularly proud that we influenced and campaigned for changes within the reorganisation of commissioning NHS specialised services in England, and supported our member groups to be centrally involved in shaping the services for their own conditions.

We are delighted to have published our Route Maps Toolkit this year. Route Maps can improve information as well as coordination of health and social care for people with rare genetic conditions, and the Toolkit will enable patient groups to devise their own condition-specific Route Map, which in turn will support many more patients and families.

This year saw the Scottish Government announce the creation of a 'Rare Disease Drug Fund'. It followed a great deal of work in partnership with other organisations and many of our member groups and families based in Scotland. We look forward to seeing the initiative providing medicines that will help many people.

Other noteable achievements this year include we were one of the first patient groups to sign up to the AllTrials campaign calling on greater transparency for clinical trial data. We were runners up in the GlaxoSmithKline and King's Fund IMPACT awards this year, meaning we were in the top 20 charities from over 400 entries. It is great to receive recognition of our work and our efforts.

Finally, we are now an alliance of 162 patient groups, uniting those affected by genetic conditions across the UK. Our aim is to keep growing our membership numbers, and to keep improving how we work with our members.

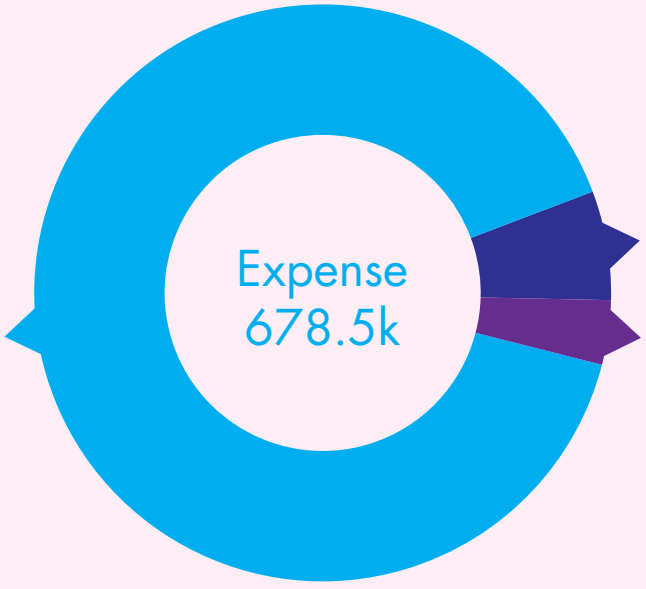
Looking ahead, next year promises to be a busy and exciting year. We look forward to working actively with members, supporters and friends as we continue to Support, Campaign and Unite on behalf of all those affected by or at risk from genetic disorders. We thank our members and all our partners for your support, and we look forward to working with you in 2013 - 2014.

Christopher J Friend
Chair

Alastair Kent
Director

Highlights of the year

- Earl Howe, Minister for Health announcing the establishment of the Rare Disease Stakeholder Forum at our parliamentary reception
- Publication of a fair and equitable All-England Commissioning Policy for preimplantation genetic diagnosis
- Our membership on the Ethics & Governance Team on the Prime Minister's 100,000 genome project
- Two SWAN UK family days for families of children with undiagnosed genetic conditions
- 350,000 unique visitors to our websites
- Charity of the Year at Genzyme Haverhill
- 162 member groups – our largest number ever
- The Scottish Government announcing the creation of a 'Rare Disease Drug Fund'



Health service development

Genetic Alliance UK advocates for improved health services, we support the acceleration of scientific innovations into healthcare that will make a difference in peoples' lives.

NHS England reorganisation

This year we have been actively influencing the decisions regarding the reorganisation of the NHS in England, ensuring that people with rare and genetic conditions are treated equitably and are able to access the services that they need.

We responded to NHS England's (previously the NHS Commissioning Board) draft mandate, emphasising that the intended Outcomes Framework should provide an equitable record of patient outcomes across the NHS, covering areas beyond access and socio-economic issues. We were clear in stating that the Framework should not marginalise and disadvantage patients with complex, rare and undiagnosed conditions.

We also responded to the Children and Young People's Health Outcomes Framework. We drew on the real-life experiences of families of children with undiagnosed genetic conditions around issues of communication, equity and respect; giving decision-makers a sense of the difference that the Framework could make to families if used effectively.

Specialised services in England

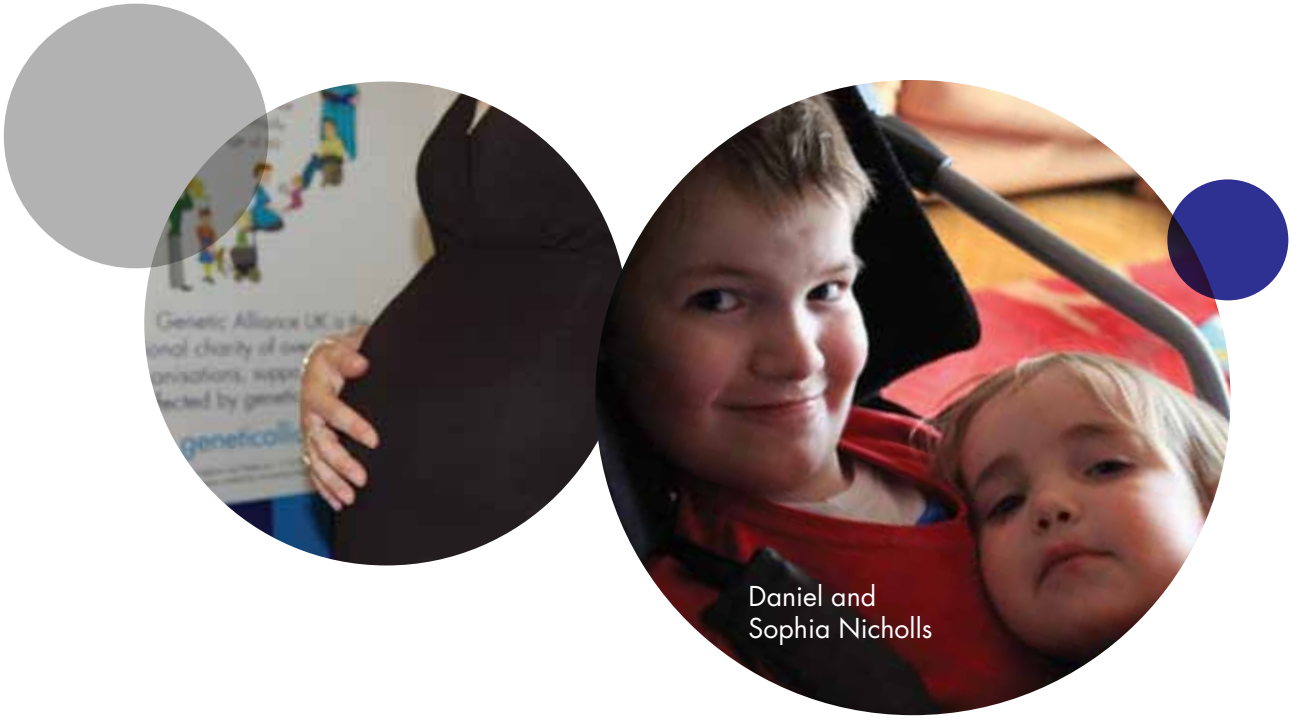
A major change for the NHS in England from April 2013 was the change to national commissioning of specialised services. Detailing the England-wide Service Specifications and Commissioning Policies were multidisciplinary groups of clinical staff, commissioners and patient or patient group representatives called Clinical Reference Groups.

We worked hard to nominate and support our own members for the Clinical Reference Groups' patient and public engagement (PPE) places. Over one-third (40 out of 112) of the PPE members for 2012-2013 were from our member groups, giving people with genetic conditions the chance to shape and influence the specialised services they need.

To support patients, families and patient groups in responding to the Clinical Reference Groups' Service Specifications and Commissioning Policies public consultation, we produced free webinars full of helpful information. No other organisation from the public, private or voluntary sector provided as much support or advice to help with this consultation. Our webinars were viewed over 450 times, and feedback from users was overwhelmingly positive.

Our Director is vice chair of NHS England's Public and Patient Engagement Steering Group and we influenced NHS England's engagement with patients and patient groups. We are pleased that from summer 2013, there will be up to four PPE members on each of the Clinical Reference Groups, strengthening the patient voice in the NHS.

We are also a member on NHS England's National Commissioning Board's ad hoc Clinical Priorities Advisory Group. This committee had the responsibility of determining national commissioning priorities of specialised services for all of England.



Developing non-invasive prenatal diagnosis services

The technology to allow non-invasive prenatal diagnosis (NIPD) for a range of single gene disorders including Down's syndrome is advancing rapidly, and gauging the opinions of women who have or are likely to use it, to inform its use is important. We asked patients and healthcare professionals what they want from such a health service.

Our research showed that women are extremely positive about a test that is both diagnostic, non-invasive, and, in many cases, provides early reassurance in pregnancy. Our research concluded that successful introduction of NIPD into routine prenatal care will require guidelines and counselling strategies which ensure women are offered this test in a way which is appropriate, informative and safeguards informed consent.

Preimplantation genetic diagnosis – access for families across England

From April 2013, preimplantation genetic diagnosis (PGD) will be nationally commissioned in England. Through our PPE role on the Medical Genetics Clinical Reference Group, we advocated for a Commissioning Policy that is fair and equitable, bringing an end to the postcode lottery.

We have been the leading patient group advocating for the availability of PGD for families with serious genetic conditions for many years. We successfully lobbied for the legislature during the passage of the Human Fertilisation and Embryology bill in 2008. Since 2009 we have provided the Human Fertilisation and Embryology Authority (the government regulator) with 111 statements of opinion for condition-specific licence applications for PGD. This year, we submitted 31 statements, meaning families affected by these conditions are now benefitting from this technology.

Over the past year, we estimate nearly 200 families have benefitted from PGD, enabling them to have a child that is free from the serious genetic condition affecting their family.

'I think we would have had a lot more heartache if PGD had not been an option. I wouldn't swap a day of our lives; it's been a real blessing'

Susanna Nicholls, a carrier of SMA type 1. Her son Daniel also has SMA1, and her daughter Sophia was conceived with the help of PGD.

"Thanks for the advice Genetic Alliance UK has provided on the NHS consultation, it was very useful."

Ataxia UK

Health service development

Genome sequencing of 100,000 patients in the UK

When the Prime Minister announced in December 2012 that up to 100,000 patients with cancers and rare diseases in the UK would have their genomes sequenced as part of a huge effort to drive cutting-edge medical science into the health-care system, we were keen to see that this would deliver real benefits to patients and to the NHS.

Our Director is one of the few patient group representatives invited by the Chief Medical Officer to be a member of the Ethics and Governance Team. This is a tremendous opportunity for us to influence the advance of personalised medicine to benefit families with rare genetic conditions through more accurate diagnosis and tailored treatments and interventions, improving health and saving lives.

Increasing access to health services for people from ethnic communities

Reducing barriers to accessing health services for genetic conditions is a key priority. This year we completed our research study 'Ethnicity & Access: Family Risk, Common Cancers and People from Minority Ethnic Groups', funded by the Big Lottery Fund and the University of Nottingham. We investigated the barriers facing people from minority ethnic groups with a significant family history of cancer in accessing clinical genetics services. The main barriers to accessing health services included language, cultural sensitivity and stigma, and social standing. We produced recommendations for NHS medical genetics service providers and commissioners. The recommendations will also be used by the communities themselves to raise awareness and advocate from their own perspective.

Screening to diagnose genetic conditions

Screening programmes are essential diagnostic tools for genetic conditions and save lives. Across the UK, NHS screening programmes are delivered differently through the devolved nations, but policy and recommendations for practice are coordinated by the UK National Screening Committee.

This year, we responded to several consultations on screening programmes for various genetic conditions including: familial hypercholesterolaemia and newborn screening programmes for severe combined immunodeficiency disease (SCID), Tay-Sachs disease, Canavan's disease and familial dysautonomia. Our take-home message to the UK National Screening Committee was that for rare genetic conditions the value of an intervention may be understood by the impact of its absence. While the criteria used by the Committee are invaluable, our message was clear that the criteria as they stand discriminate against rare genetic conditions because of their rarity. This is both unfair and a disadvantage for their potential inclusion in future screening programmes.

We are the patient group member on the Newborn Screening Board in Wales. This year we worked alongside NHS Wales to ensure that medium-chain acyl-CoA dehydrogenase deficiency (MCADD) screening was introduced in summer 2012 and that sickle cell screening will begin in summer 2013.

Rare diseases

Our campaign dedicated to improving healthcare for the 3.5 million people living with a rare disease in the UK has gone from strength to strength, and this year was its most productive yet. By March 2013, Rare Disease UK's membership was at 1,300.

Spring 2012 saw the four UK health departments jointly publish the consultation for the National Plan for Rare Diseases. We dedicated our efforts to helping the rare disease community respond to the consultation and deliver a clear message on the issues that mattered to them.

We hosted a series of free events, in England, Northern Ireland, Scotland and Wales where 250 people attended. We provided information, shared expert opinion and encouraged people to make their own responses. We also produced a series of free interactive webinars with live question and answer sessions, downloaded over 400 times; and published briefing documents, downloaded over 1,400 times. We received fantastic feedback on the events, webinars and the supporting material.

The four UK governments received over 350 consultation responses. In our analysis of the responses it was reassuring to see consensus on the major issues. In the year ahead, we will be concentrating our efforts to ensure the four UK governments publish a National Plan for Rare Diseases that can deliver better health services and care.

Rare disease day – 28 February 2013

This year's theme was 'Rare Disorders Without Borders', and we focused our activities on a series of parliamentary receptions to raise awareness of our campaign.

At Westminster we launched our report on the value of care coordinators for rare diseases. The reception was hosted by Liz Kendall MP and the Minister for Health, Earl Howe, attended and accepted the report and its findings. At our reception, the Minister announced that the Department of Health would be launching a Rare Disease Stakeholder Group to further inform the development of the Rare Disease National Plan.

At Edinburgh we launched our report on the experiences of patients and families with rare diseases living in Scotland. Our evening reception was sponsored by Malcolm Chisholm MSP and attended by the Health Minister Alex Neil MSP.

In Cardiff we launched our report on the experiences of patients and families with rare diseases living in Wales. The reception was sponsored by Mark Drakeford AM, who has since become Health Minister for the Welsh Government.

Our activities in Northern Ireland continue to flourish as a part of the Northern Ireland Rare Disease Partnership. This year, an all-Ireland event was held in Dublin, organised alongside a group of Irish charities. Northern Ireland Health Minister Edwin Poots spoke at the event.

Approximately 600 people attended the four events, demonstrating the enthusiasm and support for our campaign. Alongside our members we lobbied politicians, keeping up the political pressure to ensure that the National Plan, when it is published in 2013, is as comprehensive as it needs to be for the NHS is to be able to respond effectively to the legitimate needs of rare disease patients and their families.

80%

of rare diseases are genetic

1 in 17 PEOPLE

will be affected by a rare disease

'This was very useful, not only in helping me to write a response to the consultation but also as a networking occasion. Many thanks for this opportunity and for leading the way.'

Trustee, Batten Disease Family Association.

Information and support

Route Maps for rare conditions

Many patients and families with rare genetic conditions have difficulty in planning and coordinating their care, support and information. We decided to tackle this by developing a resource called a Route Map that helps rare disease patients coordinate their own health and social care. Our Route Maps for Rare Conditions Toolkit, funded as part of a wider project by the Department of Health, aims to help small patient groups design a Route Map for their own condition.

We worked with ten of our smallest groups to produce their own condition-specific Route Maps. Evaluating these Route Maps demonstrated improved access to information for patients, families and health and social care professionals, leading to increased awareness and understanding of the conditions. We will continue to make sure many other groups hear about how a Route Map for their condition can help their families.

SWAN UK

Our second year of running the SWAN UK (Syndromes Without A Name) network for families of children with undiagnosed genetic conditions has been fantastic. Funded by the Big Lottery, SWAN UK brings families together – sharing experiences, information and supporting each other. At the end of this year, we have 560 registered members and over 800 members using our thriving Facebook group. More families join this unique and friendly community every day.

This year's achievements have been about coming together in many different ways. We have embraced social media to reach out to families in their own homes, to fit around when they have the time to talk with others. Our blogs and moderated online forums offer peer support in an engaging way and include a dads group and regional groups. We also send out regular newsletters and updates to all families so as not to exclude those who are not online.

We held two family days and had a number of local events across the UK – Christmas parties, trips to museums and even a mums' night out! This year we piloted local SWAN support networks – families meeting up in their local area, reducing their sense of isolation and being a part of a group there especially for the benefit of their family.

An amazing achievement this year has been the fundraising that families and supporters have done. People have sky dived, organised swimathons, and shaved their heads to support more SWAN UK initiatives. We are grateful to everyone who has fundraised for us this year.

We have also been working with families to inform and influence healthcare professionals and policy makers about what's important to families who are without a diagnosis. We have also visited seven NHS regional genetics services, where families are meeting clinical teams to give them a direct understanding of life without a diagnosis.

'It's just great if you are worried or concerned... you can post on the SWAN UK Facebook page and immediately feel less alone.'

'The Route Map is fantastic! It's a one-stop-shop for everything I needed to know'

Parent whose son has Obliterative Bronchiolitis (OB) commenting on the OB Trust's Route Map.

Championing biomedical science

Genetic Alliance UK advocates for a strong and flourishing research community. We focus on ensuring that innovation in research and development is translated and commissioned into health services to address unmet health needs and improve patient outcomes.

Avoiding mitochondrial diseases with biomedical therapies

A national consultation by the Human Fertilisation and Embryology Authority (HFEA) on technologies for avoiding mitochondrial diseases was a focus of our work this year. Our Director was a member on the HFEA Oversight Working Group, enabling us to ensure the consultation considered the views of patients and families with mitochondrial diseases. In March 2013, the HFEA published its consultation findings recommending that this scientific technique should be researched and developed to find safe and effective ways of avoiding mitochondrial disease.

Partnering with leading organisations including Muscular Dystrophy Campaign, Newcastle's Centre for Life, Progress Educational Trust, Science Media Centre and the Wellcome Trust, we communicated the key issues to other opinion leaders, achieved substantial media coverage in the UK press and disseminated our informative, accessible, cartoon-style leaflet to de-mystify the science involved.

Increasing understanding of animals in medical research

The use of animals in medical research is a challenging area for many. This year with Understanding Animal Research, we piloted a project that engages patients and families with researchers investigating their particular condition to learn for themselves about the use of animals in medical research. Feedback from the project was very positive with participants expressing an interest in the area in order to help them speak openly and publically about the benefits of animal research.

Biobanks and public support

This year, we asked the general public what might encourage or discourage them to participate in biobanking. A biobank is a type of repository that stores biological samples (usually human) for use in research. Biobanks are an important tool in helping us to understand more about different diseases such as genetic conditions. Our research was funded by the Technology Strategy Board.

We discovered a high level of public support for biomedical research and willingness to donate samples for this purpose, but that there were underlying concerns about the use of certain types of samples, the conditions under which they are used, and data security. We are publishing our findings in peer review journals, including the British Medical Journal, and we will be using the evidence to inform decision makers and practitioners to influence their practice.

Access to medicines

Value based pricing of new medicines

With the clock counting down to January 2014 and the introduction of a new pricing system for medicines in the UK that is to be based on 'value', we have continued to be vocal in this debate. We support a system which pays more for medicines that bring greater value to patients and the healthcare system, while ensuring that the system is consistent, robust and equitable. We have communicated our priorities to the UK government and to other interested groups - that the system should assess value based on patient outcomes and helps to foster innovation.

Access to medicines in Scotland

In Scotland this year, we successfully raised attention to the issue of access to medicines for rare diseases amongst politicians and policy makers. Our Public Petition called for the Scottish Government to review the mechanism and methodology used by the Scottish Medicines Consortium to appraise the value of medicines for orphan diseases and to instruct the Chief Medical Officer to revise the criteria for accessing Individual Patient Treatment Requests in relation to orphan diseases. Following consideration by the Health and Sport Committee in November 2012, the Scottish Government announced a review into access to medicines in the NHS.

We were delighted when the Scottish Government announced in January 2013 that it was launching a 'Rare Disease Medicine Fund' to cover the cost of medicines for individual patients with rare conditions, which are not available for routine prescription. This announcement recognised the need for patients with rare diseases to be able to access the medicines that they need.

Working with regulators

This year, we have helped the European Medicines Agency by introducing them to patients and patient groups who are invited to review information leaflets on the medicines they are licensing. Involving the intended beneficiaries of the medicine provides the best possible review for such resources and brings the regulator into closer and better working relationships with patients and patient groups, building on future opportunities of collaboration and partnership. We hope to continue developing this collaboration and also build on this work with the UK regulator, the Medicines and Healthcare products Regulatory Agency (MHRA).

Working in Europe

Many of our key policy issues are regulated, governed or decided in Europe. To have the greatest influence and impact, we work in collaboration with other patient groups from across the continent to ensure we achieve lasting change for the benefit of our members and their families.

This year, through the European Genetic Alliance Network (EGAN), we led on a consultation response for the European Commission's Regulation on Advanced Therapy Medicinal Products. This regulation will cover stem cell therapies, tissue therapies and gene therapy, and is one where we wish to ensure appropriate law-making that will also enable research and therapies to be developed and given to patients.

Collaboration in Europe: Spotlight on EUCERD

We are an active member of EUCERD (European Union Committee of Experts on Rare Diseases). Charged with aiding the European Commission with the preparation and implementation of Community activities in the field of rare diseases, EUCERD works in cooperation and consultation with the specialised bodies in European member states. The Committee's work includes delivering recommendations or reports to the European Commission either at the latter's request or on its own initiative, and assisting the Commission in drawing up guidelines, recommendations and any other action defined in the Commission Communication. EUCERD is a valuable forum for us to influence policy decisions made at a European level and make sure UK patients and families with genetic conditions benefit.

"Thanks for the advice Genetic Alliance UK has provided on the NHS consultation, it was very useful."

Julie Greenfield Ataxia UK.

"Your support for organisations and patients in dealing with this consultation are superb."

Susan Walsh CGD Society.

Looking ahead

The year ahead for 2013 – 2014 will be a busy period for Genetic Alliance UK and we look forward to creating and seizing the opportunities to influence and inform change for the benefit of our members and families.

Our policy priorities include the long-awaited publication and implementation of the National Plan for Rare Diseases. We will be active with our members in keeping up the pressure on politicians across the whole of the UK, ensuring the Plan's content can help lever changes for the better and that its detail will be measureable to identify that it makes an improvement in peoples' care.

Other policy priorities will include issues on access to medicines: particularly NICE's extending role in developing an appraisal process for highly specialised therapies, the appraisal criteria of orphan medicines in Scotland and in Wales, and also the implementation of value based pricing for branded medicines in the UK.

We also look forward to publishing findings of our 'Risks and Benefits: the European perspective' project – which will be reporting on the view across Europe on how patients with serious medical conditions and their families perceive the balance between the risks and the benefits of new biomedical therapies.

The changes in the NHS in England will be fully underway in this year. Here we will carefully monitor the new system and will be actively communicating to NHS officials and clinical staff about the needs of our members and families. In Scotland, we will launch our Cross Party Group for rare diseases in Holyrood, another powerful tool to bring out key messages to politicians. In Wales, we will be investigating access to specialised services and therapies and in Northern Ireland we will continue our successful partnership with the Northern Ireland Rare Disease Partnership.

We will continue to develop information and support that will be helpful to our members, individuals and families. This year, we will be further increasing our collaborations with our membership, working ever closer with them in all our activities.

We are looking forward to launching our online resource 'Navigating the NHS Maze' which maps out the four health services of the UK for patients and their families, helping them understand who is accountable for delivering their health services. Our SWAN UK network will also continue to grow – we hope to get out and about, providing more direct support to families in their own communities.

Although the economic climate for the year ahead will be difficult, we will continue to secure the funding necessary that will enable us to build on our achievements and deliver more benefits to patients, their families and our members.

Trustees' Annual Report

Year ending 31 March 2013

The Board of Trustees of Genetic Alliance UK (who are also directors of Genetic Alliance UK Ltd for the purposes of company law) present their annual report together with the audited financial statements of Genetic Alliance UK Ltd (the company) for the year ending 31 March 2013.

They confirm that the annual report and audited financial statements of the company comply with the current statutory requirements, the requirements of the company's governing document and the provisions of the Charities Statement of Recommended Practice (SORP) 2005. Reference and administrative details of the charity are on the back page of this annual report.

Aim and objectives

Genetic Alliance UK aims to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. The objects of the charity are to:

- relieve persons suffering from genetic disorders;
- advance the education of the public concerning genetic disorders.

Public benefit

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit regarding section 4 of the Charities Act 2011 when implementing current and planning future activities which demonstrate the above aim and objectives.

Board of trustees

Christopher Friend - Chair*
Joanie Dimavicius - Vice Chair*
Richard West - Honorary Treasurer*#
John Dart#
Professor John Dodge#
Sally George*
Christopher Goard*
Dr Mike Knapton
Dr Mary Petrou
Dr Marita Pohlschmidt

*Member of the Finance & General Purposes Committee
Reappointed until 2015

Observers

Corinna Alberg
Dr Hilary Burton
Caroline Harrison
Dr Fiona Hemsley
Professor Shirley Hodgson
Dr Tessa Homfrey
John Kempton
Fiona Macrae
Dr Sowmiya Moorthie
Dr Liz Nelson
Robin Nott
Nicole Yost

Company secretary

Christopher Goard

Director

Alastair Kent OBE

Auditor

Nyman Libson Paul Chartered Accountants, Regina House, 124 Finchley Road, London NW3 5JS

Bankers

CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ

HSBC, Lion House, 25 Islington High Street, London N1 9LJ

Governing document

Genetic Alliance UK is the trading name for Genetic Alliance UK Ltd, a registered charity and a company limited by guarantee, incorporated on 16 April 2006 and governed by its Memorandum and Articles of Association.

Appointment and training of trustees

Trustees are responsible for the overall governance of Genetic Alliance UK. Trustees are elected by the membership; nominees must be proposed and seconded by the membership. Trustee appointments are for three years, after which they retire but are eligible for reappointment. New trustees receive induction from existing trustees and senior members of staff. Trustees are provided with an information pack detailing the charity's work, its governance and management policies and procedures, and potential conflicts of interest that may arise. Trustees are often involved in ongoing work, giving them a better understanding of the charity's work and prepare them for effective and informed decision-making.

Governance and organisational management

Trustees met five times in the year ending 31st March 2013, where they set the strategy, operating plans, budgets and reviewed the charity's performance. Trustees delegate certain powers in connection with the charity's management and administration to the Finance and General Purposes (F&GP) committee, which is convened six times a year. The committee comprises of five trustees and senior members of staff, but all trustees receive the papers and may attend the meetings. The F&GP committee reports back to the full Board of Trustees, ensuring all decisions made are fully ratified.

Trustees' Annual Report

Trustees have delegated day-to-day management of Genetic Alliance UK to the Director, who reports to the trustees.

The Director is assisted by senior members of staff, and has responsibility for planning strategies for Genetic Alliance UK Ltd subject to policy guidelines determined by the trustees.

Risk management

Trustees have considered the major risks to which the charity is exposed and have established formal procedures including a risk register to identify and manage those risks. All risks are reviewed regularly at Board of Trustees and F&GP committee meetings. Significant risks include:

- Financial sustainability: Maintaining income levels is essential, and we are pursuing diverse activities and opportunities to generate income. We implement procedures for authorisation of all transactions, controlling and regularly review our expenditure.
- Retention of staff: We recognise the expertise and skills of our staff is what enables us to pursue our charitable aims effectively. We aim to give staff a high level of job satisfaction where they feel fulfilled, supported and can develop their career.
- Preserving our reputation: Our reputation is essential to achieve our charitable activities to maximum benefit and impact. In undertaking new activities and collaborations, we consider whether they fit with our aim and objectives and our ethical principles policy.

Statement of trustees' responsibilities

The trustees (who are also directors of Genetic Alliance UK Ltd for the purposes of company law) are responsible for preparing the Trustees' Annual Report and the Financial Statements in accordance with applicable law and United Kingdom Accounting Standards.

Company and charity laws require 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 the incoming resources and application of resources including the income and expenditure of the charitable company for that period. In preparing these financial statements the trustees are required to:

- select suitable accounting policies and apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- observe the methods and principles in the charity's Statement of Recommended Practice (SORP);
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on a '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 which disclose with reasonable accuracy at any time, the financial position of the charitable company and which enables them to ensure that financial statements financial statements comply with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 (as amended). They are also responsible for safeguarding the assets of the charitable company and for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Treasurer's letter and financial review

This is my first year as Honorary Treasurer and although our income has decreased this was mainly due to two large organisations reducing their membership fees and a reduction in grant income. Against this we have reduced our expenditure where possible.

Overall in a difficult year we have managed to increase our reserves through tight budgetary controls.

The expenditure of the organisation has been used to support our mission of "Supporting, Campaigning and Uniting".

In order to reduce our expenditure, the very difficult decision was made in 2011 - 2012 to reduce salaries. The trustees decided to reinstate the salaries some five months later in 2012 - 2013. We would like to publicly thank the staff for continuing to work with us to safeguard our financial position in a difficult year.

We have a healthy pipeline of projects where we have submitted proposals to work with others on various projects supported by the EU and UK funders. We continue to seek out other projects that fall within the objectives of the Charity that would be of benefit to our members.

We would particularly like to acknowledge and thank Nancy Leslie a former trustee of the charity who left a generous legacy upon her death. This equated to about 50% of our unrestricted surplus for the year.

Richard West
Honorary Treasurer

Review of financial position

Income for the year reduced by 9% to £721,041 (2012: £792,755). This was mainly due to a reduction of donations of £15,132 (12% decrease) and reduced grant income of £55,316 (9% decrease). Our expenditure reflected a positive position in being £678,477 (3%) less than last year (£699,624). Our financial position for the year was therefore carefully monitored.

Principal funding elements

Our incoming resources are mainly membership subscriptions £36,095 (5%), donations £112,792 (15%), and project income £571,397 (80%).

Our resources and direct expenditure on restricted project work increased by £41,615 but our unrestricted expenditure reduced by £62,752. To maintain and deliver our objectives via the projects £33,998 was transferred from unrestricted to restricted funds in the year.

Reserves policy

The free unrestricted reserves policy is to provide sufficient funds for a phased closure and to be able to support work that meets our objectives but for which no external grant is available. Closure is not an option that Trustees are considering but our unrestricted reserve at March 2013 of £66,419 would have been sufficient for such eventuality.

Provision of information to auditors

Each of the persons who are trustees at the time when this Trustees' Annual Report is approved has confirmed that:

- there is no relevant audit information of which the charitable company's auditor is unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

Auditors

In accordance with section 485 of the Companies Act 2006, a regulation proposing that Nyman Libson Paul be reappointed as auditors will be put to the Annual General Meeting. In preparing this report, the Trustees have taken advantage of the small companies exemptions provided by section 415A of the Companies Act 2006

This report was approved by the trustees on 1st July 2013 and signed on their behalf by:

Christopher Friend
Chair

Independent auditor's report

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31st March 2013 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes. These financial statements have been prepared under the accounting policies set out therein.

This report is made solely to the company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the Charity's Trustees, as a body, in accordance with section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an auditor's 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 company and the company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of Trustees and auditors

The Trustees' responsibilities 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), and for being satisfied that the financial statements give a true and fair view, are set out in the Statement of Trustees' Responsibilities.

We have been appointed auditors under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report to you in accordance with those Acts.

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, have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice and have been prepared in accordance with the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

We also report to you whether, in our opinion, the information given in the Trustees' Annual Report is consistent with those financial statements.

Basis of audit 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 judgments made by the Trustees in the preparation of the financial statements and of whether the accounting policies are appropriate to the charity'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.

Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2013 and of its incoming resources and application of resources, including its income and expenditure, the year then ended;
- the financial statements have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities; and
- the financial statements have been prepared in accordance with the Companies Act 2006, the Charities and Trustees Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Opinion on other matters prescribed by the Companies Act 2006

In our opinion the information given in the Trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the Trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies' exemption in preparing the Trustees' report.

Jennifer Pope

Senior Statutory Auditor, for and on behalf of Nyman Libson Paul, Chartered Accountants and Registered Auditors
Regina House, 124 Finchley Road, London NW3 5JS
on 1st July 2013

Statement of financial activities

Company number: 05772999
for the year ended 31 March 2013

	Note	Restricted funds 2013 £	Unrestricted funds 2013 £	Total funds 2013 £	Total funds 2012 £
Incoming resources					
Incoming resources from generated funds					
Voluntary income	2		112,792	112,792	127,924
Membership subscriptions	3		36,095	36,095	37,706
Investment income	4		757	757	412
Incoming resources from charitable activities					
Grants receivable	5	571,397		571,397	626,713
Total incoming resources		571,397	149,644	721,041	792,755
Resources expended					
Cost of generating funds					
Costs of generating voluntary income			25,250	25,250	40,375
Costs of charitable activities		578,964	34,681	613,645	621,752
Governance costs			39,582	39,582	37,498
Total resources expended	6	578,964	99,513	678,477	699,624
Net income before transfers		(7,567)	50,131	42,564	93,130
Transfers between funds	11	33,998	(33,998)	-	-
Net movement in funds for the year		26,431	16,133	42,564	93,130
Total funds at 1 April 2012		50,146	50,286	100,432	7,302
Total funds at 31 March 2013		76,577	66,419	142,996	100,432

Balance sheet

Company number: 05772999
As at 31 March 2013

	Notes		2013		2012
			£		£
Fixed assets					
Tangible assets	9		-		2,003
Total fixed assets			-		2,003
Current assets					
Debtors	10	105,545		125,712	
Cash at bank		255,771		299,391	
Total current assets		361,316		425,103	
Creditors					
Amounts due within one year	12	(218,320)		(326,673)	
Net current assets			142,996		98,430
Total assets less current liabilities			142,996		100,433
Charity funds					
Restricted	11		76,577		50,147
Unrestricted funds	11		66,419		50,286
Total charity funds			142,996		100,433

The financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006 and in accordance with the Financial Reporting Standard for smaller entities (effective April 2008)

The financial statements were approved by the Trustees on the 1st of July 2013 and signed on their behalf, by:

Chris Friend, Chair Richard West, Honorary Treasurer

The notes on pages 22 to 28 form part of these financial statements.

Notes to the financial statements

for the year ended 31 March 2013

1 Accounting policies

1.1 Basis of preparation of financial statements

The financial statements have been prepared under the historical cost convention, with the exception of investments which are included at market value, and in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008). The financial statements have been prepared in accordance with the Statement of Recommended Practice (SORP), "Accounting and Reporting by Charities" published in March 2005, applicable accounting standards and the Companies Act 2006.

1.2 Incoming resources

All incoming resources are included in the Statement of Financial Activities (SOFA) when the company is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Donations are accounted for when received and membership subscriptions on a receivable basis.

Grants are accounted for on an accruals basis and are allocated as follows:

a) to Donations, Legacies and Gifts if it is considered that the payment has no particular service requirements,

b) to Income Arising from Charitable Activities if it does not fall in category (a) above.

Investment income is recognised on a receivable basis.

1.3 Resources expended

Expenditure is charged to the Statement of Financial Activities (SOFA) on an accruals basis as a liability is incurred and is classified as follows:

a) Cost of generating funds - This comprises all costs incurred by the charity associated with attracting voluntary income to finance its charitable objectives.

b) Charitable expenditure - This comprises all expenditure incurred by the charity in the delivery of its activities and services relating to the projects undertaken and includes specific staff and consultancy costs.

c) Support costs - This comprises central costs including salaries, accommodation costs and other expenses necessary to support the activities. These costs have been allocated to each activity on a basis consistent with the use of resources.

d) Governance costs - This comprises all costs associated with meeting the constitutional and statutory requirements of the charity and include the audit cost of £3,600.

1.4 Pensions

The charity does not operate a pension scheme for its employees but does contribute to the personal pension scheme of relevant staff members' choice. The company contributed 7% of salary to staff with a pension scheme before October 2011 and 3% for new schemes thereafter.

1.5 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.

1.6 Tangible assets and depreciation

Tangible assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost of fixed assets, less their residual value, over, their expected useful lives on the following basis:

Computer equipment - straight line 3 years.

1.7 Operating leases

Rentals under operating lease are charged to the statement of financial activities on a straight line basis over the lease term.

1.8 Foreign currencies

Monetary assests and liabilities denominated in foreign currencies are translated into sterling at rates of exchange ruling at the balance sheet date.

Transactions in foreign currencies are translated into sterling at the rate ruling on the date of the transaction.

Exchange gains and losses are recognised in the Statement of Financial Activities.

1.9 Taxation

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

2 Donations and grants

	Restricted funds 2013	Unrestricted funds 2013	Total funds 2013	Total funds 2012
	£	£	£	£
Genzyme		1,166	1,166	7,500
GlaxoSmithKline		43,000	43,000	40,000
Legacy		10,000	10,000	-
Medical Research Council		10,000	10,000	10,000
Other donations		10,231	10,231	924
Pfizer		2,000	2,000	-
Shire		2,395	2,395	-
St George's Hospital		-	-	1,500
The Hospital Saturday Fund		1,000	1,000	-
The Violet & Milo Cripps Trust		-	-	5,000
University of Manchester		-	-	10,000
Wellcome Trust		33,000	33,000	50,000
XL Charity of the Year		-	-	3,000
Voluntary income	-	112,792	112,792	127,924

3 Activities for generating funds

	Restricted funds 2013	Unrestricted funds 2013	Total funds 2013	Total funds 2012
	£	£	£	£
Membership subscriptions	-	36,095	36,095	37,706

4 Investment income

	Restricted funds 2013	Unrestricted funds 2013	Total funds 2013	Total funds 2012
	£	£	£	£
Interest receivable	-	757	757	412

5 Grants receivable

	Restricted funds 2013	Unrestricted funds 2013	Total funds 2013	Total funds 2012
	£	£	£	£
Citizen's Jury Risks & Benefits	9,311		9,311	72,355
Discovery Days	10,330		10,330	-
Ethnicity & Access	41,409		41,409	100,532
Ethnicity & Access 2	40,000		40,000	-
Eupati	15,145		15,145	131
Eurogenguide	(45,261)		(45,261)	(2,498)
Eurogentest 2	35		35	6,698
Facilitating Networks	-		-	78,238
Genetic Alliance UK in Scotland	21,115		21,115	21,115
Genetics & Insurance	14,703		14,703	297
Information Pathways	-		-	29,509
Navigating the Maze	32,522		32,522	-
NERRI	309		309	-
Patient Engagement in Scotland	5,000		5,000	10,413
Patient Partner	-		-	21,787
Paving the Way	-		-	13,670
PGD	24,000		24,000	-
PHGEN 2	-		-	(502)
RAPID	28,803		28,803	43,345
Rare Disease UK	122,940		122,940	106,583
RDUK Stakeholder Engagement	29,192		29,192	558
Risks & Benefits 2	18,000		18,000	-
Route Maps for Rare Conditions	64,138		64,138	64,023
STRATUM	62,309		62,309	15,058
SWAN BLF	55,625		55,625	53,733
SWAN Jeans for Genes	-		-	(10,138)
SWAN Children in Need	3,728		3,728	-
SWAN Tesco	517		517	-
SWAN General public funding	17,527		17,527	1,806
	571,397	-	571,397	626,713

*The many funders for these projects are acknowledged in the annual report.

6 Total resources expended

The costs of generating funds, charitable activities expenditure and governance costs by the allocation of direct and support costs.

Costs directly allocated to activities	Membership & fundraising	Information & education	Governance	Restricted funds	Total 2013	Total 2012
Specific project work	£	£	£	£	£	£
Staff costs				333,546	333,546	221,666
Consultancy & professional fees				44,683	44,683	36,035
Conferences & partner fees				21,720	21,720	105,298
Travel & subsistence				19,250	19,250	21,644
Website				3,592	3,592	630
Other attributable costs				16,147	16,147	18,613
Support costs in relation to activities						
Staff costs	22,727	31,605	33,107	67,639	155,078	203,908
Occupancy & administration costs	453	1,753	453	72,387	75,046	77,458
Travel & subsistence	1,403	655	1,754		3,812	0
Legal & professional fees					0	3,470
Audit & accountancy fee			3,600		3,600	8,899
Depreciation	667	668	668		2,003	2,003
	25,250	34,681	39,582	578,964	678,477	699,624

7 Trustees' benefits and renumeration

None of the trustees (or any persons connected with them) received any remuneration during the year.

Trustees were reimbursed a total of £549 (2012: £526) in respect of travelling expenses.

8 Employees

	2013	2012
The average number of employees during the year was:	14	15

	2013	2012
	£	£
Wages and salaries	430,497	375,625
Social security costs	43,510	36,750
Pension costs	14,617	13,201
	488,624	425,576

One employee earned more than £50,000

During the year the charity made pension contributions in respect of 7 employees (2012: 7).

9 Tangible fixed assets

Cost	Computer equipment 2013	2012
	£	£
At 1 April 2012	6,009	6,009
Additions	-	-
At 31 March 2013	6,009	6,009
Depreciation		
At 1 April 2012	4,006	2,003
Charge for the year	2,003	2,003
At 31 March 2013	6,009	4,006
Net Book value		
At 31 March 2013	-	-
At 31 March 2012		2,003

10 Debtors

	2013	2012
	£	£
Trade debtors	78,222	669
Other debtors	3,752	7,489
Prepayment and accrued income	23,571	117,554
	105,545	125,712

11 Statement of funds

	Brought forward £	Incoming resources £	Less resources expended £	Transfers in/(out) £	Carried forward £
Unrestricted funds					
General funds - all funds	50,286	149,644	99,513	(33,998)	66,419
Restricted funds					
Citizen's Jury Risks & Benefits	3,231	9,311	12,542		-
Discovery Days	-	10,330	3,732		6,598
Ethnicity & Access	19,240	41,409	60,649		-
Ethnicity & Access 2	-	40,000	31,313		8,687
Eupati	-	15,145	15,342	197	-
Eurogenguide	(1,687)	(45,261)	(14,335)	32,613	-
Eurogentest 2	741	35	744		32
Genetic Alliance UK in Scotland	143	21,115	20,804		454
Genetics & Insurance	-	14,703	14,703		-
Navigating the Maze	-	32,522	31,980		542
Nerri	-	309	309		-
Patient engagement in Scotland	9,654	5,000	1,701		12,953
PGD	-	24,000	12,092		11,908
PHGEN 2	(658)	-	(77)	581	-
RAPID	10,492	28,803	31,825	607	8,077
RDUK	(127)	122,940	120,814		1,999
RDUK SEE	-	29,192	29,192		-
Risks & Benefits 2	-	18,000	16,478		1,522
Route Maps for Rare Conditions	161	64,138	60,294		4,005
Stratum	1,250	62,309	63,559		-
SWAN BLF	5,900	55,625	53,073		8,452
SWAN Children inNeed	-	3,728	3,728		-
SWAN Tesco	-	517	517		-
SWAN General public funding	1,806	17,527	7,985		11,348
	50,146	571,397	578,964	33,998	76,577
Total of funds	100,432	721,041	678,477	-	142,996

*The many funders for these projects are acknowledged in the annual report.

Each restricted fund is for a specific project for which Genetic Alliance UK receives a grant and the income and fund balance are only spent on the purposes for each individual project

11 Statement of funds continued

	Brought forward £	Incoming resources £	Resources expended £	Transfers in/(out) £	Carried forward £
Summary of funds					
General funds	50,286	149,644	99,513	(33,998)	66,419
Restricted funds	50,146	571,397	578,964	33,998	76,577
	100,432	721,042	678,477	-	142,996

12 Creditors

	2013 £	2012 £
Trade creditors	36,794	26,983
Other creditors	13,370	6,880
Accruals and deferred income	168,156	292,810
	218,320	326,673

13 Analysis of net assets between funds

	Restricted funds 2013	Unrestricted funds 2013	Total funds 2013	Total funds 2012
Tangible fixed assets	-	-	-	2,003
Current assets	273,265	88,051	361,316	425,103
Creditors due within one year	(196,688)	(21,632)	(218,320)	(326,673)
	76,577	66,419	142,996	100,433

14 Operating lease commitments

At 31 March 2013 the company had annual commitments under non- cancellable operating leases as follows:

	2013 £	2012 £
Expiry date:		
Within one year	3,095	3,348
Between one and five years	8,865	4,856

Acknowledgements

Many individuals and organisations have supported and helped us in delivering our work this year. We take this opportunity to show our gratitude and thank them.

Volunteers

We regularly utilise the skills of volunteers recruited from our member groups or other stakeholders. We estimate that 100 people helped us in our work during the course of the year. These volunteers often have direct personal or professional experience of genetic conditions. We also have access to a network of contacts in both the lay and professional communities. These people provide advice, support and specific inputs to our activities as and when the need arises. We are very grateful to all who support our work in a voluntary capacity. Thank you.

Funders

We are grateful to everyone who has supported us financially this year. A special thank you goes to all the individuals and families who have fundraised for us; we also received a legacy donation this year. We also thank the following funders who have given generously the following grants, donations and sponsorship this year.

Aegon
Actelion
Alexion
Association of the British Pharmaceutical Industry
Assurance Medical and Underwriting Society
AstraZeneca
Baxter
BBC Children in Need
BIG Lottery Fund
BioMarin
Biomedical Research Education Trust
CSL Behring
Department of Health Third Sector Investment
EU Sixth Framework
EU Seventh Framework
Friends Life
Genzyme
GlaxoSmithKline
Hospital Saturday Fund
Innovative Medicines Initiative
Legal & General
Medical Research Council
Merck Sharp & Dohme
MunichRe
National Institute for Health Research
Novartis
Pfizer
Raptor
RGA
Royal London
Scottish Government
ScorRe
Shire
Sigma Tau
SwissRe
Technology Strategy Board
Tesco Charity Trust
UCB
UK Forum for Genetics and Insurance
Understanding Animal Research
University of Nottingham
Unum
Viropharma
Wellcome Trust

We thank GlaxoSmithKline for covering the costs of printing and delivery of this Annual Report.

Membership

Our membership is at the heart of our work and we were delighted that our membership grew to 162 members by 31st March 2013. We are very grateful to every single member as it demonstrates recognition in the value of our work. Our members are:

Action for Sick Children (Scotland)

Action on Gilbert's Syndrome

Adrenal Hyperplasia Network

Advocacy for Neuroacanthocytosis Patients

aHUSUK

Albinsim Fellowship

ALD LIFE

Alkaptonuria Society

Alpha 1 Awareness UK

Alstrom Syndrome UK

Amy and Friends

Androgen Insensitivity Syndrome Support Group

Aniridia Network UK

Anorchidism Support Group (ASG)

Anthony Nolan

ARC

Arthrogryposis Group (TAG), The

Assert

Association of Multiple Endocrine Neoplasia Disorders (AMEND)

Ataxia - Telangiectasia Society

Ataxia UK

Barth Syndrome Trust

Batten Disease Family Association

Beckwith-Wiedemann Support Group

Behcets Syndrome Society

Breathtakers Charity

British Heart Foundation

British Porphyria Association, The

Cancer Research and Genetics UK

Cardiomyopathy Association

Cavernoma Alliance UK

CDLS Foundation

CGD Research Trust

ChILd Lung Foundation

Childhood Eye Cancer Trust

Chromosome 18 Registry and Research Society (Europe)

CLIMB

CMT United Kingdom

Cohen Syndrome Support Group

Confer Scotland

Congenital Adrenal Hyperplasia Support Group

Costello Support Group (International)

Cri Du Chat Syndrome Support Group

DBA-UK

DEBRA

Down's Heart Group

Dravet Syndrome UK

Duchenne Family Support Group

Dyskeratosis Congenita Society

East London Branch Sickle Cell Society

Ectodermal Dysplasia Society

Ehlers-Danlos Support Group

Eyeless Trust, The

Familial Alzheimer's Disease Support Group

Fanconi Hope

FAP UK

Friends of Kabuki Syndrome

FSH Muscular Dystrophy Support Group

Fuchsfriends UK

Galactosaemia Support Group

Gauchers Association

Gorlin Syndrome Group

HAE UK

Haemochromatosis Society

Haemophilia Society

Headlines Craniofacial Support

HITS (UK) Family Support Network

HME Support Group

HSP Support Group

Huntington's Disease Specialist Service

Huntington's Disease Association

Huntington's Disease Association (Colchester Branch)

Huntington's Disease Association Northern Ireland

Hypermobility East Anglia Group

Hypoparathyroidism (HPTH) UK

Ichthyosis Support Group

Jewish Genetic Disorders UK

Keratoconus Self Help and Support Group

Klinefelter Organisation (UK)

Klinefelter's Syndrome Association

Laurence Moon Bardet Biedl Society

The Lipoprotein Lipase Deficiency Community

Making it Better - The Daniel Courtney Trust

Manchester Sickle Cell and Thalassaemia Centre

Marfan Association UK

Marfan Trust

Max Appeal
Medical Advisory Service
Moebius Research Trust
Mosaic Down Syndrome UK
Motor Neurone Disease Association
Mowat-Wilson Syndrome Support Group
Muscular Dystrophy Campaign
Myotonic Dystrophy Support Group
Myrovlytis Trust
Naitbabies.org
Narcolepsy UK
National Sickle Cell Programme
Nemaline Myopathy
Nephrotic Syndrome Trust
Niemann-Pick Disease Group (UK)
Noonan Syndrome Assocation
Noonan UK
NSPKU
OSCAR
Osteopetrosis Support Group
Pemphigus Vulgaris Network
Peutz Jeghers Syndrome Support Group
PID UK (Genetic Disorders UK)
Plagiocephaly Care UK
PNH Support Group, King's College Hospital
Polycysitc Kidney Disease Charity
Prader Willi Syndrome Association UK
Primary Ciliary Dyskinesia Family Support Group
PVNH Support and Awareness
PXE Support Group
Restricted Growth Association
RP Fighting Blindness
Rubinstein Taybi Support Group
SADS UK
Save Babies Through Screening Foundation UK
Scottish Huntington's Association
Shwachman-Diamond Support UK
Sickle Cell and Young Stroke Survivors
Society for Mucopolysaccharide Diseases
SOFT UK
STEPS - Association for People with Lower Limb Abnormalities
Stickler Syndrome Support Group
Tar Support Group
Telangiectasia Self Help Group
The 22 crew
The Association for Glycogen Storage Diseases (UK), The
The Brittle Bone Society
The Cavan Tommy Hoey Trust (Ireland)
The Children's Mitochondrial Disease Network
The Cogent Trust
The Cystic Fibrosis Trust
The Fragile X Society
The Frontotemporal Dementia Support Group (formerly, Pick's Disease Support Group)
The Hypermobility Syndrome Association
The Information Point for Centronuclear and Myotubular Myopathy
The International Autistic Research Organisation
The Jennifer Trust for Spinal Muscular Atrophy
The Neuro Foundation
The Sickle Cell Society
The Thalidomide Society
The Von Hippel Lindau Contact Group
Thyroid UK
TRPS Support Group UK
Tuberous Sclerosis Association
Turner Syndrome Support Society (UK)
UK Thalassaemia Society
UKPIPS
UK Potsies
Unique- The Rare Chromosome Disorder Support Group
Usher Service - SENSE
Vasculitits UK (SSVT)
Williams Syndrome Foundation Limited
Wilson's Disease Support Group
Worster Drought Syndrome Support Group
XLP Research Trust
XP Support Group

Genetic Alliance UK
Supporting. Campaigning. Uniting.

Reference and administrative details

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Registered Charity Numbers:	1114195 and SC039299
Registered Company Number:	05772999
Twitter	@GeneticAll_UK
Facebook	GeneticAllianceUK