Genetic Alliance UK
Supporting. Campaigning. Uniting.

Annual Report and Accounts

for Genetic Alliance UK ltd

2014 – 2015

Welcome to our Annual Report and Accounts

for 1 April 2014 – 31 March 2015

The first half of our report includes an overview of our achievements in this year and our plans for the future. The second half of our report includes the trustees' report, our financial statements and accounts for the year.

Public benefit

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit and have complied with their duty under section 4 of the Charities Act 2011 when reviewing the charity's aims and objectives; and in implementing current and planning future activities.

Contents

About us

Genetic Alliance UK is the national charity of over 180 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. Often, genetic conditions are inherited and can affect more than one member of the family. Few genetic conditions can be cured and many have no effective treatments. Patients and families often have a high level of unmet need – they frequently experience delays in gaining an accurate diagnosis and may struggle to access appropriate care and support.

It is vital that medical research sheds light on these conditions in order to develop effective interventions and therapies and that these 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

80%

of rare diseases are genetic conditions

Letter from the Chair and the Director

2014/15 has undoubtedly been one of our busiest and most successful years: the 10 highlights listed opposite could easily have been 20.

Genetic Alliance UK is now firmly established as a key patient voice in healthcare decision-making. We extended our series of influential patient charters, summarising patient priorities on topical issues such as genome sequencing and these documents have become viewed as a blueprint for bringing a constructive, collaborative patient voice to the heart of healthcare decision-making. We were also commissioned by Genomics England to gather the views of the patient community on issues relating to the Department of Health's flagship 100,000 Genomes Project.

Our Rare Disease UK (RDUK) initiative remains the leading patient voice in the development of the *UK Strategy for Rare Diseases*, playing an active role at every step of its implementation.

Genetic Alliance UK's strength lies in being a user-led organisation. Harnessing the unique expertise and insight that patients and families possess, and promoting the value of their experiences will always be fundamental to our effectiveness. An important focus of our work this year has been on our interactions with our member groups and with patients and families. In particular:

Supporting - our SWAN UK Local Networks project involves partnership working with eight parents of children with undiagnosed conditions to develop a model for on-the-ground support for families in their local area.

Campaigning - our patient charter on genome sequencing, based on the views of 100 patients and family members, has informed the work of Genomics England's Ethics Advisory Group.

Uniting - 86 of our member groups endorsed our Patient Charter on NHS England's specialised commissioning.

2015 is Genetic Alliance UK's 25th anniversary year. We are delighted to be entering our silver jubilee year in such a strong position, with our community closer than ever. We look forward to 2015/16 with much excitement!

Christopher Goard, Chair of the Board of Trustees

Alastair Kent OBE, Director

Highlights of the year

Our Welsh Development Officer appeared as an expert witness before the House of Commons' Welsh Affairs Select Committee. Her evidence fed into recommendations to improve access to cross-border services for rare disease patients.

The My Condition My DNA project's innovative methods for engaging patients and family members in debate around genome sequencing from their own homes and our first GenomeSeqWeek to launch the findings.

Our SWAN UK Local Networks project is providing on-the-ground, parent-led support for families of children with undiagnosed genetic conditions in six areas and developing a model with potential for much wider roll-out.

Our three Rare Disease Day events at Westminster, the Scottish Parliament and the Welsh Assembly were our most successful yet: attended by over 600 people and Earl Howe, the Minister in charge of rare diseases, described our Westminster event as "one of the landmark events of my year".

The EUPATI Expert Training course in medicines and development, which we helped to produce, was released to the first cohort of 50 trainees from across Europe.

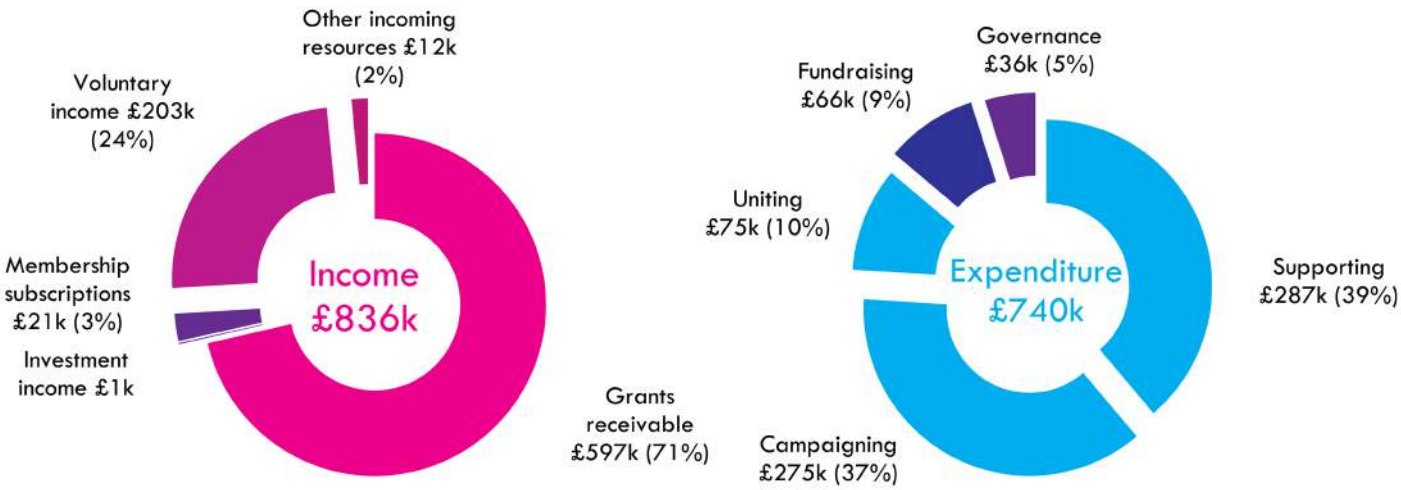
Our Patient Charter on NHS England's specialised commissioning was adopted by NHS England's Patient and Public Voice Assurance Group as a basis for a new 'manifesto' for patient engagement within NHS England.

Our work with the Scottish Government, facilitating two stakeholder workshops, enabled patient groups to feed into the development of the Scottish Plan for Rare Diseases.

Rare Disease UK secured the Highly Commended Award in the Excellence in Communications - Payers/Policymakers category of the Communiqué Awards 2014.

Reaching a wider audience than ever before: growing support for all of our networks, over 10,000 people following our Twitter feeds; and our specially-designed Rare Disease Day Facebook poster reaching almost 60,000 people.

A SWAN UK parent received a standing ovation for her speech at the prestigious House of Fraser Charity Event. House of Fraser has since confirmed SWAN UK as a full charity partner for the event in 2015.



Supporting

SWAN UK – supporting families of children with undiagnosed genetic conditions

SWAN UK has continued to thrive. We have significantly extended the scope of our work, both by reaching new families and by providing more intensive local support through our new SWAN UK Local Networks project.

At a national level, we now provide regular, ongoing support to over 1,000 families of children with undiagnosed genetic conditions across the UK, providing practical advice, signposting families to relevant genetic research studies and other services and working with health, social care and education professionals to highlight the issues faced by undiagnosed families.

We also actively bring families together for peer support through our lively online community of almost 950 families and through face-to-face meet-ups across the UK. This year we have organised a total of 23 events for SWAN UK families, including family fun days in special needs play centres, Christmas parties and outings to a range of family-friendly attractions.

"So special to meet and unite with our SWAN UK family and to see the delightful smiles and joy on the children's faces as they embraced the day! A very good day had by all with many new friendships made!" SWAN UK parent

Over the last year, the support we provide to families beyond England has become more established. In November, working closely with families and health care professionals in Northern Ireland, we organised an Undiagnosed Genetic Conditions Information Event in Belfast. The event was the first of its kind in Northern Ireland and was warmly welcomed by both professionals and families.

"I was delighted that there was a conference for undiagnosed syndromes here in Northern Ireland as I felt we were on our own over here." SWAN UK parent

A strong support network has also developed in Scotland. Scottish SWAN UK families now meet regularly for mutual support and information-sharing and we have organised a number of family events, including popular outings to Blair Drummond Safari Park and The Falkirk Wheel.

SWAN UK families continue to play a central role in determining the initiative's direction and priorities. In May, responding to a need for local support, we launched a new project - SWAN UK Local Networks. This provides on-the-ground, parent-led support to families of children with undiagnosed genetic conditions in six areas of England - Bedfordshire, Birmingham, Essex, Halifax, Newcastle and Gateshead and Nottingham. The project also involves working closely with parent volunteers to develop a replicable model which we plan to roll-out across the UK over the next few years.

"Being able to meet other parents locally who are going through the same thing, with

the same professionals is invaluable and such a support" SWAN UK parent

Our work as SWAN UK is attracting a growing community of fundraisers and funders, and we are often touched by their loyalty and enthusiasm. As well as a steady stream of fundraising activities taking place throughout the year, in April around 20 families, companies, schools and community groups organised fundraising events to support our 2nd annual Undiagnosed Children's Day, and our first-ever SWAN UK runner took part in the Virgin London Marathon. In July, nominated by a SWAN UK member, we were thrilled to be chosen as one of the causes to be supported at the prestigious House of Fraser Charity Event.

My Condition, My DNA: supporting patients in understanding genome sequencing

This ground-breaking project supported over 100 patients and family members in understanding genome sequencing and the social and ethical issues around it, preparing the patient community for the use of this new technology in mainstream clinical practice.

The project used a range of engagement methods to ensure that participants could get involved in the project from their own home, including podcasts of fictional scenarios, webinars, video clips, quizzes and live web-chats. This approach enabled a broad range of patients and families to participate in the project, including those with chronic ill-health, disability or caring responsibilities.

"Thank you so much for streaming the webinar. It was especially interesting and enabled (potentially) anyone to participate; at whatever level they felt comfortable from wherever they were across the globe" My Condition, My DNA project participant

The key findings from patients, together with a series of recommendations, were presented in a patient charter, 'Genome sequencing: What do patients think?', launched at a high-profile reception at the Wellcome Trust in February. Nearly 100 attendees and over 100 people from across the world watching online heard the Life Sciences Minister, George Freeman MP, give the keynote speech. We were pleased that he was able to hear first-hand about patient views on genome sequencing.

The launch was part of a week of events, GenomeSeqWeek, to increase public dialogue on genome sequencing and support a wider audience in understanding this important new technology. These included: a Twitter take-over by Vivienne Parry OBE and Dr Anna Middleton, a screening of the award-winning documentary 'Do You Really Want to Know?' which follows three families who must decide whether or not to be tested for Huntington's disease, a science cafe-style event at a pub in central London - 'Will genomic data be used or abused?' and the first-ever patient group trip to the Wellcome Trust Sanger Institute.

Supporting

"My husband and I found the day to be fascinating. We thought the talks that were given were pitched at just the right level - interesting and slightly technical to give more information than may be got from just reading. It made us think about our daughter and has bought some further questions to mind to discuss with our neurologist." Wellcome Trust Sanger Institute trip participant

EUPATI Expert Training Course: supporting patients to develop expertise in medicines development

As partners in the EUPATI (European Patients Academy on Therapeutic Innovation) project, we contributed to the development of the course syllabus for the Expert Training Course. This offers a unique and exciting opportunity for patients and patient advocates to take part in expert-level training in medicines research and development, through a mixture of independent e-learning and face-to face training. The first group of 50 participants from across Europe started the 14–month course in October.

I would encourage anybody who wants to know more about medicine research & development to consider applying to the EUPATI Course. The ability to study online at your convenience, while having a diverse team of experts at your finger tips to answer your questions and to provide you with extra information if wanted is pretty unique." Marleen Kaatee, President PSC Patients Europe, The Netherlands

Helping Patients Help Themselves: developing peer support networks for rare and genetic conditions in Scotland and Wales

Condition-specific patient networks often provide a life-line to people living with rare and genetic conditions, offering a source of information, opportunities for peer support and a means to contribute to the development of effective services. The Helping Patients project works closely with patients and families to establish and develop responsive and dynamic networks or patient groups, where none currently exist. Building on a highly successful pilot in Scotland, we have extended the project to include Wales, with a UK-wide project due to start in 2015.

Since the end of 2014, we have been working with patients and families to establish a Welsh network for Restless Legs Syndrome (also known as Willis Ekbom Disease). The network is thriving, with regular drop-in sessions in South Wales and a new website and Twitter page. We have also been working to develop a network for rare inherited eye diseases in South Wales.

Our work in Scotland continues to grow, for example supporting patients with Joint Hypermobility Syndrome (JHS) living in the west of Scotland to set up regular peer support meetings.

"Coming to a support group made me realise that I can get better" JHS suppport group member

Campaigning

Genetic Alliance UK continues to campaign at a UK, devolved nation and EU level. We have responded to over 40 consultations, including on the Medical Innovation Bill, the mitochondrial donation regulations and the European data sharing regulation. We have produced 13 briefings for parliamentarians and members, on issues such as access to rare disease medicines and individual funding requests.

We have partnered with our members: with ARC (Antenatal Results and Choices) to produce a briefing on the parliamentary vote on abortion on the grounds of fetal sex; and campaigning with the Lily Foundation, Muscular Dystrophy UK and others on the mitochondrial donation regulations.

We have maintained a high profile and significant influence through our membership of committees and advisory groups across the UK and Europe. Our staff represent patients and families on more than 50 committees and groups. In particular we have established a strong presence within the NHS, with representation on 19 NHS groups across the UK, including the Rare Disease Advisory Group, the Specialised Commissioning Oversight Group, the Welsh Health Specialised Services Committee and the National Services Division Public Reference Group. Our Director continues to act as Chair of the UK Rare Disease Forum.

Patient charters: campaigning to bring the patient voice to the heart of healthcare decision-making

We have published three highly successful charters, covering major issues relevant to our members. These are compelling and authoritative documents, that summarise the patient perspective on a particular issue and make recommendations for healthcare policy-makers. The charters have been widely praised, by key organisations such as NICE and Genomics England, as constructive, collaborative documents and an effective means of bringing the patient voice to the heart of healthcare decision-making.

"The patient charter really is excellent and I'm sure you are very proud of this piece of work which is crucial to all of those patients and families who have been touched by a rare disease." Kathy Oliver, The International Brain Tumour Alliance (IBTA)

Patient perspectives and priorities on NICE's evaluation of highly specialised technologies

Our first patient charter, launched in March 2014, has continued to have an impact. Since April 2014 we have:

- Co-hosted a Parliamentary roundtable with the BioIndustry Association (BIA) to discuss the findings with MPs and Peers. This led directly to Lord Walton and Lord Hunt asking related questions on this issue.
- Continued to monitor the Highly Specialised Technology programme, contribute to scoping meetings and attend Evaluation Committee meetings. Information we gather will inform our response to the consultation on proposed highly specialised technology evaluations, expected next year.
- Contributed to a workshop on the future of patient involvement in NICE. The Novartis-run workshop identified many of the same recommendations as the charter.

Campaigning

Patient perspectives and priorities on NHS England's commissioning of medicines for rare diseases

Our second patient charter built on feedback from 30 patient group members gathered at a two-day workshop, with six overarching recommendations for positive change to NHS England's commissioning approach. Endorsed by 86 patient groups, It was launched at Great Ormond Street Children's Hospital in October. The high-profile panel discussion was attended by nearly 100 policy-makers, healthcare professionals and patient representatives. The charter has been downloaded over 600 times, and the day after its launch viewed by over 9,000 people on our Facebook page.

"Congratulations on completing what surely was a mammoth task in drawing this all together - a really massive and incredibly difficult piece of work." Jayne Spink, Tuberous Sclerosis Association

Since publication, the charter has been universally well-received. In particular it has:

- been adopted by NHS England's Patient and Public Voice Assurance Group to form the basis of a new 'manifesto' for their patient engagement.
- been referenced in the House of Lords in questions to the Government about improving the process to assess medicines used for treating rare diseases.
- formed the basis of a number of our consultation responses on this issue, reinforcing that our policy work is being driven directly by the views of patients and our member groups.

"[the charter] pulls together a complex and ever-changing environment into an easy to understand and very readable document which I believe will be highly valued by many organisations struggling to understand access to rare medicines." Debra Morgan, Pfizer

Genome sequencing: what do patients think?"

Our third patient charter, published in February, was based on findings gathered through our My Condition, My DNA project. This included 15 recommendations for consideration before genome sequencing becomes widely incorporated into NHS services. Since the charter's publication:

- It has been discussed at Genomics England's Ethics Advisory Group and the European Commission's Expert Group on Rare Diseases.
- We have been approached by the Institute of Cancer Research to replicate the project with a focus on cancer patients.
- We were asked to present the findings of our work at the European Society of Human Genetics conference in Glasgow in June 2015.

Rare Disease UK: campaigning for the *UK Strategy for Rare Diseases*

Rare Disease UK (RDUK) remains the largest patient coalition in the UK, with membership now at 1,700, including 260 patient organisations. It commands a large audience with over 6,000 followers on Twitter and 1,300 on Facebook. The last year has been fast-paced and eventful:

- Our second conference as part of the Europlan project sought to agree a common standard for delivering healthcare services for rare disease patients. This will inform national rare disease plans across the EU.

RARE DISEASE | UK

- We established the Patient Empowerment Group (PEG), bringing together representatives of 30 patient groups to provide a coherent patient voice on the implementation of the *UK Strategy for Rare Diseases*. The PEG will monitor the strategy's implementation and campaign on issues of concern to patients. In September, the PEG met with David Walker, the Deputy Chief Medical Officer in England and lead for rare diseases.
- In July, RDUK secured the Highly Commended Award in the Excellence in Communications - Payers/Policymakers category of the Communiqué Awards. 2014

"This campaign had some highly impressive achievements, at a time when everything would seem to have been working against them. To have engagement and traction with 250 patient groups and all four jurisdictions of the NHS is an indication that they've got it right and are doing all the right things" Judges at the Communique Awards

- We continued to add to the knowledge base on the rare disease patient experience, launching a new report, 'Patient experiences of transition between care providers', at our first-ever All Party Parliamentary Group (APPG) Summit on Rare Diseases. The summit brought together five APPGs connected to rare disease and was hosted by Diane Abbott MP, Chair of the APPG on Sickle Cell and Thalassaemia. It also marked the first anniversary of the UK Strategy's publication.
- This year's Rare Disease Day was marked with events across the UK, supported by health ministers in each nation. The events focused on the theme of 'living with a rare disease, day-by-day, hand-in-hand', emphasising the challenges in the daily lives of patients, families and carers. Over 600 delegates attended across the UK.

"One of the landmark events of my year" Rt Hon Earl Howe, Parliamentary Under Secretary of State for Quality, on our Westminster Rare Disease Day event

In Scotland, we continued to raise awareness of rare diseases with the Scottish Parliament's Rare Diseases Cross Party Group, for which we provide the secretariat. The Group met four times across the year, discussing the Scottish Plan for Rare Diseases, research into rare diseases, access to medicines and coordination of care. In May, we worked closely with the Scottish Government to facilitate two workshops for patient groups to feed into the development of the Implementation Plan for Rare Diseases.

Our Development Officer for Wales sits on the Clinical Evidence and Evaluation Group (CEEG) for Rare Diseases, set up by the Welsh Health Specialised Services Committee (WHSSC) to determine commissioning priorities and improve access to specialised services and therapies. Our team has also supported the Welsh Government, organising a patient group consultation meeting to feed back on the draft Welsh Implementation Plan for Rare Diseases as well as supporting development of the final Implementation Plan, due for release imminently.

Uniting

Every aspect of Genetic Alliance UK's work seeks to unite people to facilitate support or bring about lasting changes in healthcare policy and practice. Over the last year we have worked closely with our member groups to provide a united voice for all those affected by genetic conditions.

Genomics England: uniting our community to influence genome sequencing

In the summer, Genetic Alliance UK was commissioned by Genomics England (GeL) to conduct a research study gathering patient views of genome sequencing. The results would inform policy development, help shape the ethics framework for the 100K Genomes Project and help prepare patient information as GeL requested ethical approval for its work. The main themes we explored were: which findings should be fed back to participants, sharing of personal information with third parties and future re-contacting of participants for further research. We conducted

"We are delighted that Genomics England has successfully secured ethics approval and look forward to working with them to deliver the best possible outcomes for patients from this ground-breaking venture" Alastair Kent OBE, Director Genetic Alliance UK

an online survey of over 230 Genetic Alliance UK and SWAN UK members, as well as telephone interviews to explore opinions in more depth. The subsequent report has been published on both Genetic Alliance UK's and GeL's websites, and Genomics England has since gone on to secure ethical approval.

Risks and Benefits: uniting patients to bring their perspective to the heart of decision-making around the regulation of medicines

Conducted in partnership with the Welsh Institute for Health and Social Care at the University of South Wales, the Risks and Benefits project explored the views of over 500 patients and family members from across the UK and Europe, gathering information on how they perceive the risks and benefits of new medicines. Findings from the research suggest that the traditional regulatory system for medicines does not meet the needs or preferences of patients with rare and/or serious conditions - a population with significant unmet medical need.

"A great example of patient preference research" Dr Isabelle Stoeckert VP, Head Global Regulatory Affairs, Europe/Canada, Bayer Schering Pharma AG

In November, we launched our research report at a well-attended event in the Welsh Government European Union Office in Brussels. The event, 'How would patients with rare and serious diseases regulate medicines?', was attended by individuals and representatives of organisations directly engaged with medicine regulation in Europe. We were delighted that the Senior Medical Officer for the European Medicines Agency spoke and allowed us to highlight the desire of many patients with rare and genetic conditions to consider greater risks in medicines development. It

also increased recognition of the importance of the patient perspective in decision-making around this complex issue.

Genetic Alliance UK Annual conference 2014: uniting our membership

In July, we held our 2014 annual conference on the theme of genome sequencing, considering how it is likely to change the future of healthcare, the social and ethical issues associated with its use and its potential impact for patients and families.

We were delighted to have keynote speakers Vivienne Parry, science writer, broadcaster, Vice-chair of University College London Council and Chair of the Communications and Engagement Committee at Genomics England and Dr Mark Bale, Deputy Head of Health Sciences and Bioethics at the Department of Health. The conference also included a dynamic interactive session with a live smartphone survey of audience opinions.

"Excellent event. Well organised. Interesting, interactive and stimulating day" Genetic Alliance UK Member

Our conference is a focal point for engaging our members in the latest advances from the research, healthcare and policy arenas. It provides a rare opportunity for patients and patient groups to meet with research scientists, healthcare professionals, industry professionals and policy makers to learn and share information, exchange ideas, discuss issues of shared concern and contribute their viewpoints to shape Genetic Alliance UK's strategic policy work.

This year, 128 delegates registered for the conference, of which 94 (84%) represented our member groups.

Uniting Scottish patients

In September, we hosted a joint consultation workshop with the Chief Scientist Office (CSO), providing our members with the opportunity to contribute a patient voice to the development of the CSO's Draft Research Strategy. We also provided a written submission to the CSO's formal consultation on the Draft Research Strategy. This came about as a direct result of our Development Officer in Scotland's work to develop strong relationships with the healthcare and research communities in Scotland, enabling our direct involvement in policy-making.

Uniting Welsh patients

Our active presence in Wales is allowing Genetic Alliance UK to provide significant input to policy development. In January, we launched our report 'Improving access to specialised services and therapies for Welsh patients' at the National Assembly for Wales. The report summarised the experiences of Welsh patients with rare diseases in accessing cross-border services as well as specialised therapies and details 14 recommendations for improving access. It also led to our Develpment Officer appearing as an expert witness at the House of Commons' Welsh Affairs Select Committee on cross border access to health care. A great achievement and a further opportunity to add the patient's voice to key policy debates.

Looking ahead

2015 is a landmark year for Genetic Alliance UK - our 25th as a registered charity. We will celebrate through a range of activities, including a special anniversary Annual Conference, where we will look back at our achievements and celebrate our role in bringing about lasting changes in healthcare provision. We enter our 25th year with a strong reputation and the skills and experience we need to take us forward. Our priorities include:

Supporting

Helping Patients: the extended two-year project will go UK-wide, working closely with patients and families across the UK to establish around 15 new patient support networks or groups, where none currently exist.

Genome sequencing: building on the success of My Condition, My DNA, we will pursue further opportunities to highlight the patient perspective on genome sequencing, developing new projects to produce patient-friendly information. We will also collaborate with the Institute of Cancer Research to look at issues for cancer and genome sequencing and plan to hold our second GenomeSeqWeek in 2016.

SWAN UK: as funding from the Big Lottery Fund enters its final year we will be reviewing our funding strategy for SWAN UK and securing new income to support the project.

Campaigning

Rare diseases: we will continue to push for the implementation of the *UK Strategy for Rare Diseases*, so that it remains an issue on the healthcare agenda throughout the UK. As part of this work, we will continue to build on our successful Pledge for Patients campaign by asking parliamentary candidates in Scotland and Wales to sign up to a pledge card to show their support and commitment to patients and families affected by rare, genetic and undiagnosed conditions.

Parliamentary engagement: we will develop an All Party Parliamentary Group (APPG) that will cover the breadth of our organisation's work, representing people with rare, genetic and undiagnosed conditions and will provide a forum for all our members to communicate with parliamentarians in Westminster. At this important stage of the *UK Strategy for Rare Diseases* and at a crucial point in the development of genome sequencing, the APPG on rare, genetic and undiagnosed conditions will be a vital tool to build new relationships, raise awareness and disseminate our ideas.

Patient Charters: we will develop charters on access to medicines in Scotland and Wales to provide a comprehensive patient-focused viewpoint on issues specific to Scotland and Wales. We will also work to deliver clarity and coordination between the different routes for accessing medicines across the UK.

Uniting

Hidden Costs: this ground-breaking project, a collaboration with Health Economist Professor Steve Morris (University College London), will study how best to research the impact (psychosocial and economic) of different service configurations in rare diseases. The project will help to build a more rounded picture of the experience of patients. Ethical approval for this project has recently been granted.

Trustees' Annual Report

The Board of Trustees (who are also directors of Genetic Alliance UK Ltd for the purposes of the Companies Act 2006), present their annual report and the audited financial statements of the charity for the year ended 31 March 2015.

Trustees confirm that the annual report and audited financial statements of the charity have been prepared in accordance with the accounting policies set out in note 1 of the financial statements, and they comply with the charity's governing document and the provisions of the Charities Statement of Recommended Practice (SORP), 2005.

Reference and administrative details for the charity are on the back cover of this report.

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 6 April 2006 and governed by its Memorandum and Articles of Association.

Aim, objectives and activities

Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all who need them. We actively support research and innovation across the field of genetic medicine.

The objectives of the charity are to:

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

Our activities are detailed in part one of this report.

Trustees

Ruth Abuzaid - Vice Chair*
John Dart (resigned 8th July 2014)
Professor John Dodge
Christopher Friend*
Sally George
Christopher Goard - Chair*
Rebecca Griffiths*
Dr Mike Knapton
Claire Mather (appointed 8th July 2014)
Rae McNairney
John Mills
Dr Marita Pohlschmidt
Dr Samantha Price (appointed 8th July 2014, resigned 17th March 2015)
Richard West - Honorary Treasurer*

* Member of the Finance & Governance Committee

Observers

Corinna Alberg
Caroline Harrison
Dr Fiona Hemsley
John Kempton (stood down 15th January 2015)
Fiona Macrae
Robin Nott
Nicole Yost
Phyllis Wong

Company Secretary

Christopher Goard

Director

Alastair Kent OBE

Management Team

Buddug Cope, Melissa Hillier,* Nick Meade, Stuart Pritchard and Stuart Watt FCCA

* resigned in July 2014

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

HSBC, 63-64 St Andrews Street, Cambridge CB2 3BZ

Appointment and training of trustees

Trustees are elected by the membership and nominees must be proposed and seconded by a member. Trustee appointments are for three years, after which trustees 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, governance, management policies and procedures, and potential conflicts of interest that may arise.

Governance and organisational management

Trustees met five times in the year ending 31st March 2015, where they determined and approved the strategy, operating plans, budget and reviewed the charity's

performance. Trustees delegate certain powers in connection with the charity's management and administration to the Finance and Governance (F&G) committee, which convened five times in the year.

The F&G committee comprises five trustees and senior members of staff, but all trustees receive the papers and may attend the meetings. The F&G committee reports back to the full Board of Trustees, ensuring all decisions made are fully ratified.

Trustees have delegated day-to-day management of Genetic Alliance UK to the Management Team led by the Director who collectively have responsibility for delivering the approved strategy.

Risk management

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

- Financial sustainability - we pursue diverse opportunities to generate income. We implement procedures for authorisation of all transactions; regularly reviewing expenditure to provide relevant information, maintain control and mitigate fraud.
- Preserving our reputation - in undertaking all new activities and collaborations, we consider whether they align with our aim and objectives, whether they will enable us to deliver on our public benefit and whether they meet our Ethical Collaboration Policy.
- Retention of knowledge and expertise - we endeavour to give staff a high level of job satisfaction where they feel fulfilled, supported and can develop their career.

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 Charities 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 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

We are very fortunate, this year, to have received an unrestricted legacy of £16,253 from the estate of a previous trustee, Nancy Leslie. This has contributed 60% of our unrestricted surplus for the year. This amount was unexpected and very welcome after the £10,000 from her estate two years ago.

Review of financial position

Overall we have an unrestricted surplus of £27,559 for the year (2014 £19,473) which is mainly due to the legacy of £16k and a reduction in expenditure of £11k to £125,398 (2014 £136,053). We are grateful for the surplus and the reduction in expenditure is a reflection of us trying to do more with less.

Principal funding elements

In the year, although we increased the number of our members, the membership fee income reduced by £5,315 to £21,620 (2014 £26,935) but against this we gained £71,824 of unrestricted grants and other income to £683,335 (2014 £611,511) including an extra £29k of general donations for our SWAN UK project. Restricted expenditure increased by £121,309 to £615,551 (2014 £494,242). This has resulted in a restricted fund surplus to carry forward of £67,784 (2014 £117,629).

This increase in unrestricted income and expenditure confirm the increased level of our activities to deliver our objectives through specific projects which engage with the public, members and stakeholders now and in the future.

Reserves policy

Our free unrestricted reserves at 31st March 2015 of £113,451 (2014 £85,892) are in line with our policy to provide sufficient funds for a phased closure, three months of general running costs, in the event of a reduction of funding and the opportunity to fund work that meets our objectives if no grant can be found.

As part of our reserves policy, all monies including restricted grants and donations received are kept secure and our bank balance £609,921 (2014 £471,373) reflects the reserves policy and the receipt in advance of funds to allow us to continue projects into the next financial year.

Conclusion

We are aware that funding opportunities in the current environment are more difficult to obtain and we thank all of our funders and members whose financial support has allowed us to continue our work to support our objectives and mission of 'Supporting. Campaigning. Uniting'.

Richard West
Honorary Treasurer

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 22nd June 2015 and signed on their behalf by:

Christopher Goard
Chair

Independent auditor's report

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2015 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.

Independent auditor's report

Genetic Alliance UK Ltd - a company limited by guarantee

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 2015 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.

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

on 22nd June 2015

Statement of financial activities

Company number: 05772999
for the year ended 31 March 2015

	Note	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
Incoming resources					
Incoming resources from generated funds					
Voluntary income	2	86,274	117,509	203,783	171,294
Membership subscriptions	3		21,620	21,620	26,935
Investment income	4		1,004	1,004	660
Incoming resources from charitable activities					
Grants receivable	5	597,061	0	597,061	534,128
Other incoming resources			12,824	12,824	34,020
Total incoming resources		683,335	152,957	836,292	767,037
Resources expended					
Cost of generating funds					
Costs of generating voluntary income		7,554	66,360	73,914	46,822
Costs of charitable activities		607,997	22,621	630,618	536,770
Governance costs			36,417	36,417	46,703
Total resources expended	6	615,551	125,398	740,949	630,295
Net income before transfers		67,784	27,559	95,343	136,742
Transfers between funds	11			-	-
Net movement in funds for the year		67,784	27,559	95,343	136,742
Total funds at 1 April 2014		193,846	85,892	279,738	142,996
Total funds at 31 March 2015		261,630	113,451	375,081	279,738

Balance sheet

Company number: 05772999
As at 31 March 2015

	Notes		2015		2014
			£		£
Fixed assets					
Tangible assets	9		-		-
Total fixed assets			-		-
Current assets					
Debtors	10	65,834		85,692	
Cash at bank and in hand		609,921		471,373	
Total current assets		675,755		557,066	
Creditors					
Amounts due within one year	12	(300,674)		(277,328)	
Net current assets			375,081		279,738
Total assets less current liabilities			375,081		279,738
Charity funds					
Restricted funds	11		261,630		193,846
Unrestricted funds	11		113,451		85,892
Total charity funds			375,081		279,738

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 22nd of June 2015 and signed on their behalf, by:

Christopher Goard, 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 2015

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 to income arising from Charitable Activities. Investment income is recognised on a receivable basis. We do not accept any income that is contingent on the charity carrying out work on behalf of a third party that would be counter to the interests of patients and families with genetic disorders or which would compromise the independence of the strategy endorsed by the Board of Trustees.

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 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 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.

1.4 Pensions

The charity contributes to the personal pension scheme of the staff member's choice. The charity contributes 7% of salary to the pension scheme when staff contribute 3% or more to it.

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 the fixed asset, less their residual value, over, their expected useful lives on the following basis: Computer equipment, above a de minimus of £1,000 - 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. An exchange loss of £6,537 is recognised in the statement of financial activities in respect of EU funded projects.

1.9 Taxation

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

2 Donations and gifts

	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
Amgen				1,000
BioMarin				1,500
B&HS Management				5,000
General donations to RDUK	736		736	1,042
General donations to SWAN UK	56,645		56,645	48,462
GlaxoSmithKline		40,000	40,000	44,000
House of Fraser	22,894		22,894	
Legacy		16,253	16,253	-
Marsh		10,000	10,000	10,000
Medical Research Council		10,000	10,000	10,000
MSD				11,458
Oxford Gene Technology				3,000
Other donations		8,255	8,255	891
Pfizer	3,500		3,500	-
Skin Care charity				1,941
St James Place Foundation	2,500		2,500	
Wellcome Trust		33,000	33,000	33,000
			-	
Voluntary income	86,274	117,509	203,783	171,294

3 Activities for generating funds

	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
Membership subscriptions	0	21,620	21,620	26,935

4 Investment income

	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
Interest receivable	0	1,004	1,004	660

Financial Report

Genetic Alliance UK Ltd - a company limited by guarantee

5 Grants receivable

	Restricted funds 2015 £	Unrestricted funds 2015 £	Total funds 2015 £	Total funds 2014 £
Access to Medicines in England [2,7,24]	22,000		22,000	
Access to Medicines in England - dissemination [24]	10,000		10,000	
Animals Disovery Days	-		-	3,000
Animals in Research [22]	35,000		35,000	
Economic Burden of Rare Disease in Europe (B.U.R.Q.O.L)	-		-	1,892
EU Patients Academy (E.U.P.A.T.I) [20]	32,429		32,429	35,199
Eurogentest 2	-		-	21,221
Genetic Alliance UK in Scotland [30]	35,208		35,208	31,551
Gen Equip - ERASMUS	475		475	
Genomics England Survey: Patient views on genomic sequencing[14]	14,454		14,454	
Helping patients help themselves: Scotland (previously Supporting patient groups in Scotland) [15,29]	13,601		13,601	5,012
Hidden Costs of Rare Diseases [15,21]	20,400		20,400	
Highly Specialised Technologies [3,25]	-		-	15,500
Information Pathways	-		-	2,100
MS Research in Scotland [25]	-		-	13,295
My Condition, My DNA [8,22,40]	47,852		47,852	13,148
Navigating the NHS Maze: Information	-		-	21,000
Navigating the NHS Maze: Training	-		-	23,000
Neuro-enhancement: Responsible Research and Innovation [15]	17,096		17,096	29,515
Patient Engagement in Scotland	-		-	6,313
Patient Engagement in Wales [3,5,15]	8,468		8,468	12,532
Producing Effective Patient Leaflets [27]	198		198	
R.A.P.I.D: Patient Experiences	-		-	6,337
Rare Disease UK - Europlan [11]	-		-	1,265
Rare Disease UK [1,3,7,9,10,15,16,23,24,25,26,28,31,32,34,36,37,38,39]	153,798		153,798	124,157
Risks & Benefits of New Medicines: Europe	-		-	62,000
Route Maps for Rare Conditions	-		-	16,385
SWAN UK: England [6]	56,444		56,444	57,415
SWAN UK: Family Fun Days [33,35]	8,300		8,300	1,483
SWAN UK: Local Networks [6]	88,808		88,808	750
SWAN UK: Information Day	-		-	5,831
SWAN UK: Northern Ireland Information Event [4]	4,186		4,186	
SWAN UK: Scotland [29]	-		-	11,012
T.A.I.N.: Patient Experiences [12]	26,844		26,844	13,214
UKNSC Webinar [15]	1,500		1,500	
*Funders are detailed in Acknowledgements on page 29	597,061	-	597,061	534,128

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	Basis of allocation	Membership & fundraising	Information & education	Governance	Restricted funds	Total 2015	Total 2014
		£	£	£	£	£	£
Specific project work							
Staff costs	Direct				346,528	346,528	267,147
Consultancy & professional fees	Direct				13,231	13,231	44,674
Conferences & events	Direct				76,959	76,959	41,669
Travel & subsistence	Direct				25,362	25,362	12,711
Website	Direct				552	552	3,315
Other attributable costs	Direct				17,113	17,113	13,754
						-	
Support costs in relation to activities						-	
						-	
Staff costs	Staff time	63,719	22,373	26,517	45,915	158,524	169,814
Occupancy & administration costs	Allocation	2,250			89,891	92,141	65,978
Travel & subsistence	Allocation	391	248	2,804		3,443	433
Legal & professional fees	Direct			1,696		1,696	6,000
Audit & accountancy fee	Direct			5,400		5,400	4,800
Depreciation	Direct		-			-	-
		66,360	22,621	36,417	615,551	740,949	630,295

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 £2,541 (2014: £1,444) in respect of travelling expenses.

£263 was paid in respect of a trustee indemnity policy.

8 Employees

	2015	2014
The average number of employees during the year was:	13	12

	2015	2014
	£	£
Wages and salaries	458,367	384,458
Social security costs	35,933	38,990
Pension costs	10,752	13,513
	505,052	436,961

One employee earned more than £50,000

During the year the charity made pension contributions in respect of 5 employees (2014: 6).

9 Tangible fixed assets

Cost

	Computer equipment	2015	2014
		£	£
At 1 April 2014		6,009	6,009
Additions		-	-
At 31 March 2015		6,009	6,009
Depreciation			
At 1 April 2014		6,009	6,009
Charge for the year			
At 31 March 2015		6,009	6,009
Net Book value			
At 31 March 2015		-	
At 31 March 2014			-

10 Debtors

	2015	2014
	£	£
Trade debtors	7,443	2,000
Other debtors	-	-
Prepayment and accrued income	58,391	83,692
	65,834	85,692

11 Statement of funds

	Brought forward £	Incoming resources £	Less resources expended £	Transfers in /(out) £	Carried forward £
Unrestricted funds					
General funds - all funds	85,892	152,957	125,398		113,451
Restricted funds					
Access to Medicines in England [2,7,24]		22,000	14,573		7,427
Access to Medicines in England - Dissemination [24]		10,000	278		9,722
Animals Discovery Days	1,245		-		1,245
Animals in Research [22]		35,000	26,200		8,800
EU Patients Academy (E.U.P.A.T.I) [20]	189	32,429	32,557		61
Genetic Alliance UK in Scotland [30]	7,322	35,208	37,717		4,813
Gen Equip - ERASMUS		475	475		0
Genomics England Survey:					
Patient views on genomic sequencing [14]		14,454	14,454		0
Helping patients help themselves: Scotland					
(previously Supporting Patient Groups in Scotland) [15,29]	70	13,601	4,176		9,495
Hidden Costs of Rare Diseases [15, 31]	24,026	20,400	28,909		15,517
Highly Specialised Technologies [3,25]	3,216	-	301		2,915
Highly Specialised Technologies Webinar [25]		3,500	-		3,500
MS Research in Scotland [15,24]	8,964	-	6,220		2,745
My Condition, My DNA [8,22,40]	5,766	47,852	40,097		13,521
Navigating the NHS Maze: Information	1,634	-	-		1,634
Navigating the NHS Maze: Training	2,923	-	-		2,923
Neuro-enhancement:					
Responsible Research & Innovation [13]	15,858	17,096	32,880		74
Patient Engagement in Scotland	15,078	-	6,659		8,419
Patient Engagement in Wales [3,5,15]	2,091	8,468	5,045		5,514
Producing Effective Patient Leaflets [27]		198	197		1
PGD: Information	1,894		-		1,894
R.A.P.I.D.: Patient Experiences	1,868	-	-		1,868
Rare Disease UK [1,3,7,9,10,15,16,23,24,25,26,28,31,32,34,36,37,38,39]	5,686	153,798	135,489		23,995
Rare Disease UK - Europlan [11]	1,205	-	1,205		0
Rare Disease UK - General Donations	2,908	736	-		3,644
Risks and Benefits of New Medicines	24,804	-	24,804		0
SWAN UK: England [6]	9,566	56,444	55,236		10,774
SWAN UK: Family Fun Days [33,35]	339	10,800	3,819		7,320
SWAN UK: Family Support 2014 [18]		22,894	7,655		15,238
SWAN UK: General Funding [17,21]	34,859	60,831	26,114		69,576
SWAN UK: Local Networks [6]	-	88,808	70,223		18,585
SWAN UK: Northern Ireland	5,083	(4,186)	164		733
SWAN UK: Northern Ireland Information Event [4]		4,186	3,075		1,111

Each fund is for a specific project for which Genetic Alliance UK receives a restricted grant or donation.

*Funders are detailed in Acknowledgements on page 29

Continued on next page

Financial Report

Genetic Alliance UK Ltd - a company limited by guarantee

11 Statement of funds continued

	Brought forward	Incoming resources	Less resources expended	Transfers in /(out)	Carried forward
	£	£	£	£	£
SWAN UK: Scotland [29]	10,799	-	10,799		0
T.A.I.N.: Patient Experiences [12]	6,454	26,844	24,731		8,567
UKNSC Webinar [15]		1,500	1,500		-
	193,846	683,335	615,551		261,630
Total of funds	279,738	836,292	740,949		375,081

Summary of funds

	Brought forward	Incoming resources	Resources expended	Transfers in/(out)	Carried forward
	£	£	£	£	£
General funds	85,892	152,957	125,398		113,451
Restricted funds	193,846	683,335	615,551		261,630
	279,738	836,292	740,949	-	375,081

12 Creditors

	2015	2014
	£	£
Trade creditors	77,664	64,157
Other creditors	2,606	1,409
Accruals and deferred income	220,404	211,762
	300,674	277,328

13 Analysis of net assets between funds

	Restricted funds 2015	Unrestricted funds 2015	Total funds 2015	Total funds 2014
	£	£	£	£
Current assets	515,418	160,337	675,755	557,066
Creditors due within one year	(253,788)	(46,886)	(300,674)	(277,328)
	261,630	113,451	375,081	279,738

14 Operating lease commitments

At 31 March 2015 the charity had annual commitments under non-cancellable operating leases as follows:

	2015	2014
Expiry date:	£	£
Within one year		
Between one and five years	3,221	3,221

15 Related party transactions

There were no related party transactions in the year.

Acknowledgements

Many individuals and organisations have helped us to deliver our work this year. We would like to say a very heartfelt thank you to them all.

Thank you to Josh Tucker for many of the photographs that appear in this annual report.

Volunteers

We greatly benefit from the skills and knowledge of all the volunteers who give their time to Genetic Alliance UK for free. We estimate that over 100 volunteers have helped us during the course of the year, with many bringing expertise from their personal or professional experience of genetic conditions. This year we would like to particularly thank:

Our trustees and observers, and specifically those who have contributed a large amount of their time to the development of our new Articles of Association and other new initiatives.

The eight parent representatives who have been involved in our new SWAN UK Local Networks project, who are working with the project team to develop a replicable model for providing local support.

The many members of Genetic Alliance UK who have made our projects and events a success. We have held a number of public events throughout the year and are always grateful for the energy and enthusiasm of members who attend or support in other ways. In particular, a number of patients and carers have contributed as speakers at our events providing an invaluable personal insight that brings to life many of the issues confronting people living with genetic conditions.

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 and especially to the huge number of SWAN UK members and supporters, whose fundraising is helping to build a solid income stream to support SWAN UK's future work.

We would like to thank the following funders who have given grants, donations and sponsorship to support our work this year:

Aegerion [1]

AbbVie [2]

Alexion [3]

Big Lottery Fund – Awards for All England

Big Lottery Fund – Awards for All Northern Ireland [4]

Big Lottery Fund – Awards for All Wales [5]

Big Lottery Fund – Reaching Communities[6]

BioMarin [7]

British In Vitro Diagnostics Association [8]

Celgene [9]

CSL Behring [10]

EU Commission – DG Sanco [11]

EU Commission – FP7 Health [12]

EU Commission – FP7 Science in Society [13]

Genetics Society

Genomics England [14]

Genzyme [15]

GlaxoSmithKline [16]

GSO Capital Partners [17]

House of Fraser [18]

Human Fertilisation and Embryology Authority [19]

Innovative Medicines Initiative [20]

John Ellerman Foundation

Law Firm Services [21]

Marsh

Medical Research Council [22]

Merck Serono [23]

Neighbourly Charitable Trust

Novartis [24]

Oakdale Trust

Pfizer [25]

PTC Therapeutics [26]

Public Health England [27]

Raptor [28]

Scottish Government – S16B [29]

Scottish Government – Strategic Funding Partnership [30]

Shire [31]

Sigma Tau [32]

Sobell Foundation [33]

Sobi [34]

St James's Place Foundation [35]

Synageva [36]

Tesco Charity Trust

UCB [37]

Vertex [38]

Viropharma [39]

Waterloo Foundation

Wellcome Trust

Wellcome Trust – People Award [40]

Numbers match funders to the grants listed on page 24 and the restricted project funds listed on page 27.

We would also like to thank Pfizer, PTC Therapeutics and SOBI for contributing to the cost of producing this annual report.

Pro bono support

Several organisations have provided us with services or resources for free this year, we thank the following for their support:

Association of British Pharmaceutical Industry

The BioIndustry Association

Cardiff University

The Donkey Sanctuary, Ivybridge

European Union Office Welsh Government

Genomics England

Goodstuff

Royal College of Paediatric and Child Health

Wales Gene Park

Welsh Assembly

Wellcome Trust

Wellcome Trust Sanger Institute

Our Members

Our members are the heart of our work. We are very grateful to every single member; their membership both strengthens our collective voice and demonstrates recognition of 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

Alström Syndrome UK

Amy and Friends

Androgen Insensitivity Syndrome Support Group

Aniridia Network UK

Anorchidism Support Group (ASG)

Antenatal Results and Choices

Anthony Nolan Trust

Assert

Association of Multiple Endocrine Neoplasia Disorders (AMEND)

Ataxia - Telangiectasia Society

Ataxia UK

Barth Syndrome Trust

Batten Disease Family Association

Beckwith-Wiedemann Support Group

Behçets Syndrome Society

Breathtakers Charity

British Heart Foundation

British Porphyria Association

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)

CML Support

CMT United Kingdom

Cohen Syndrome Support Group

Confer Scotland

Congenital Adrenal Hyperplasia Support Group

Costello Support Group (International)

Cri Du Chat Syndrome Support Group

DEBRA

Diamond Blackfan Anaemia Support Group UK

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

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

GIST Support UK

Gorlin Syndrome Group

HAE UK

Haemochromatosis Society

Haemophilia Society

Headlines Craniofacial Support

HITS Worldwide

HME Support Group

HPS Network UK

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 UK

Hypopara UK

Ichthyosis Support Group

Jeune Syndrome Foundation

Jewish Genetic Disorders UK

Keratoconus Self Help and Support Group

Klinefelter Organisation (UK)

Klinefelter's Syndrome Association

Laurence Moon Bardet Biedl Society

Making it Better - The Daniel Courtney Trust

Manchester Sickle Cell and Thalassaemia Centre

Marfan Association UK

Marfan Trust

Max Appeal

Our Members

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 Trust

Pemphigus Vulgaris Network

Peutz Jeghers Syndrome Support Group

PID UK (Genetic Disorders UK)

Plagiocephaly Care UK

PNH Support Group

Polycysitc Kidney Disease Charity

Prader Willi Syndrome Association UK

Primary Ciliary Dyskinesia Family Support Group

PVNH Support and Awareness

PXE Support Group

Ragdolls UK

Restricted Growth Association

Reverse Rett

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

SPARKS

Spinal Muscular Atrophy Support UK

STEPS Charity

Stickler Syndrome Support Group

Tar Support Group

Telangiectasia Self Help Group

The 22 Crew

The Arthrogryposis Group (TAG)

The Association for Glycogen Storage Diseases UK

The Brittle Bone Society

The Cavan Tommy Hoey Trust (Ireland)

The Children's Mitochondrial Disease Network

The Cogent Trust

The Cure and Action Tay Sachs Foundation

The Cystic Fibrosis Trust

The Fragile X Society

The Frontotemporal Dementia Support Group

The Hypermobility Syndrome Association

The Information Point for Centronuclear and Myotubular Myopathy

The International Autistic Research Organisation

The Lily Foundation

The Lipoprotein Lipase Deficiency Community

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 Potsies

UK Thalassaemia Society

UKPIPS

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.

Genetic Alliance UK is the trading name of Genetic Alliance UK ltd

Reference and administrative details

Address:	Unit 4D, Leroy House 436 Essex Road London, N1 3QP
Telephone:	+44 (0)20 7704 3141
Fax:	+44 (0)20 7359 1447
Email:	contactus@geneticalliance.org.uk
Website:	www.geneticalliance.org.uk raredisease.org.uk undiagnosed.org.uk
Registered Charity Numbers:	1114195 and SC039299
Registered Company Number:	05772999
Twitter	@GeneticAll_UK, @rarediseaseuk and @SWAN_UK
Facebook	GeneticAllianceUK, RareDiseaseUK and SWANchildrenUK