GENETIC ALLIANCE UK ltd
Report of the Board of Trustees and Accounts 2016–2017
REPORT OF THE BOARD OF TRUSTEES
for the year ended 31 March 2017

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 2017. The trustees have adopted the provisions of Accounting and Reporting by Charities

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Cover photo: Gillian Thomas (speaker), Tess Harris (CEO, The PKD Charity), Dr Larissa Kerecuk (Rare Disease Lead for Birmingham Children’s Hospital) at the 2016 Genetic Alliance UK ltd AGM
Photograph: Joshua Tucker

Genetic Alliance UK ltd
(A company limited by guarantee)
Company number: 0577 2999
Registered charity numbers: 1114 195 (England and Wales) SC03 9299 (Scotland)
contactus@geneticalliance.org.uk
www.geneticalliance.org.uk
WELCOME FROM THE CHAIR

On 21 April this year I had the bittersweet task of making a speech to mark the retirement of our long standing Director Alastair Kent. In 1993, Alastair joined the organisation as its first employee and has since served with creativity, passionate dedication and as everyone who knows him will attest, considerable wit. Alastair occupied this role for 24 years – with a record of achievements that have cumulatively led to substantial improvements and benefits for patients and families affected by genetic conditions across the UK. On a personal level my ten-year working relationship with Alastair was not only productive but also a pleasure and helped us to work effectively together for patients, members and staff. We collectively owe a great debt of gratitude to Alastair and wish him every success for the future.

In saying goodbye to Alastair, we welcome Jayne Spink PhD as the incoming Chief Executive of Genetic Alliance UK. I am delighted to say that Jayne has, in her first few months, already made a real impact on our way of working that gives me real confidence her contribution will go from strength to strength. This bodes well for members, patients, staff and trustees and for the future of Genetic Alliance UK. I feel too that this would be the right time for me to step down as Chair of the Board of Trustees of Genetic Alliance UK so I intend to make the year ahead my final year as Chair. We are in the process of recruiting a new Chair of the Board of Trustees to continue our strategic drive, but I am delighted to have contributed in my limited way to the charity over the last ten years and expect it to continue to develop and become ever more successful in supporting members and beating the drum for patients and families affected by genetic conditions.

This year the trustees have taken the decision to separate Genetic Alliance UK’s impact report from the Report of the Board of Trustees. This will give Jayne and her team the opportunity of presenting their vision of the future of Genetic Alliance UK alongside the impact of this year’s activities in a new publication that will facilitate the development of funding opportunities, relationships and new collaborations.

Autumn of 2016 saw the London office move from Canonbury to Queen Square, thanks to a rental arrangement with Great Ormond Street Hospital for Children NHS Foundation Trust. We would like to express our gratitude to the Trust for facilitating this relocation, which has already paid dividends in bringing improved connections with our stakeholders.

This year the team and trustees collaborated to produce a values document that describes the values of Genetic Alliance UK. These are being fed into all the activities of the organisation from recruitment to our day-to-day activity to ensure we continue to live our values and apply them in all that we do.

Chris Goard
Chair
Board of Trustees
Genetic Alliance UK ltd
OBJECTIVES AND AIMS

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 190 patient organisations.

The objectives of the charity are to:

- relieve persons affected by a genetic condition(s);
- advance the education of the public concerning genetic conditions in such ways as the trustees of the charity think fit.

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.

We seek to raise awareness of genetic conditions and improve the quality of services and information available to patients and families. We actively campaign on issues of policy and practice to influence governments, policy makers, industry and care providers such as the National Health Service. We provide a united voice for all those affected by genetic conditions, enabling us to work together towards a common goal of making life better for patients and families at risk.

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.

Nicola Blackwood MP, the Minister with responsibility for rare diseases, addresses the Westminster Rare Disease Day reception Photograph: Joshua Tucker
ACHIEVEMENTS AND PERFORMANCE

Information and communication
This year we re-vitalised and significantly improved our online presence, bringing together the websites of Genetic Alliance UK, the Rare Disease UK campaign and the SWAN UK support network into a single accessible website at geneticalliance.org.uk. In the nine months since the launch of the website, there was a rise in unique monthly visitors of 89%, from 7,421 at the end of July 2016 to 14,030 at the end of March 2017, demonstrating the increased relevance and visibility of our website’s content.

Our commitment to producing trustworthy and quality assured information and the continued quality of our products is evidenced by the renewal of our Information Standard accreditation in January 2017.

During the year we improved our communication to members, with 79 email newsletters published. Our social media reach also improved across our social media channels. Genetic Alliance UK’s twitter feed gained 2,000 followers, to reach 8,200; Rare Disease UK’s gained 3,100, to reach 12,300; SWAN UK’s gained 1,200 to reach 6,400. Between the three feeds, our tweets were viewed 4.9 million times. Rare Disease UK published 17 blogs of members’ stories and SWAN UK published 62 members’ blogs. Our patient experience videos were viewed 32,000 times across Facebook and YouTube.

We were pleased to be finalists for the Communique Awards in the category of Charity, Patient or Professional Association of the Year.

Membership and engagement
Our membership continues to grow, and in this year rose from 183 at the beginning of the year to 195 members at its close. We were pleased to be able to involve our members in an increased proportion of our work. We aim to empower our member groups through upskilling their own staff and volunteers, and by engaging them with the most important and relevant issues that affect people with genetic conditions today.

The Building Rare Communities project, which works with patients and families across the UK to establish and develop support networks or patient groups, where no condition-specific support groups previously existed, inducted 17 new potential groups this year.

We engaged with our members to produce reports on attitudes to genome sequencing (commissioned by Genomics England), and to genome editing (an output from the European Commission funded ‘NERRI’ project on neuroenhancement on which we were partners). With the 100,000 Genomes Project due to end in the coming year, genome sequencing is expected to become part of mainstream healthcare delivery. The voices of our members will be crucial in ensuring that the project’s legacy is beneficial to those affected by genetic conditions in the future. Genome editing as a technology is just beginning to show its potential; here our members’ voices can ensure that progress in this field is directed towards the development of cures and treatments for genetic conditions.

Policy and public affairs
The voices of small organisations representing patients with rare genetic conditions are all too easily lost or marginalised. Genetic Alliance UK’s work with our members brings hundreds of these voices together from across the community into unified messages that we can take to the heart of the debate in Cardiff Bay, Holyrood, Stormont and Westminster.

This year, we responded to 14 relevant consultations and provided 42 statements of patient and family experience to the Human
Fertilisation and Embryology Authority to support the regulation of preimplantation genetic diagnosis. This work would not have been possible without the expertise of our members, who made it possible to directly feed the voice of families affected by genetic conditions into the responses.

Staff presented at a wide range of national and international fora, including the 2016 European Conference on Rare Diseases and Orphan Products in Edinburgh, which we helped to organise.

The public affairs team ran its Pledge for Patients Campaign for the Scottish and Welsh Government elections in 2016. We secured 115 pledges of support from prospective candidates, of which 43 were elected. This work will allow us to reconvene a Cross Party Group in Scotland and to launch the same in Wales.

This was the first full year of the Westminster All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed Conditions, for which we provide the secretariat. The group was chaired by Ben Howlett MP. In May the APPG launched its first report. This described the experience of families with children with undiagnosed genetic conditions who have participated in genome sequencing research projects and made recommendations to improve their experience. The APPG hosted a preliminary event on access to rare disease medicines in England and was a contributor to a collaborative APPG event briefing Parliamentarians on the implications of Brexit for medical research and regulation.
The APPG held a series of hearings on the implementation of the UK Strategy for Rare Diseases in England, publishing a report on Rare Disease Day, 28 February 2017. The main recommendation of the report was that the Department of Health develop an implementation plan for England. This was accepted by Philip Dunne MP, Minister of State for Health, in a Westminster Hall debate a month later as he announced a coordinating role for the Department.

Our Rare Disease UK campaign has grown to more than 2,000 supporters including more than 300 patient organisations; this initiative is the most significant and representative vehicle influencing the policy landscape for rare and genetic conditions in the UK. The work of the campaign continues to focus on implementation of the UK Strategy for Rare Diseases with the intent of realising the tremendous benefits to our community, on topics such as care coordination, care pathways, and research collaboration. Rare Disease Day 2017 was celebrated with our annual parliamentary receptions and with six twitter takeover events and four new patient experience videos. Corporate support for the project year ending December 2016 grew too, generating £221,766 of income.

Genetic Alliance UK’s work on access to medicines for rare diseases continued with a workshop on the Welsh Government’s decision-making processes. We participated in 10 scoping meetings for rare disease medicines at NICE, and continued to contribute to wider NHS decision making processes with our membership of various advisory groups and reference groups across the country. Last year’s Patient Charter on Access to Rare Disease Medicines in Scotland proved influential in the Montgomery Review in Scotland. Through formal positions, we continue to advise a broad range of stakeholders in genetic healthcare including Association of British Insurers, Departments of Health, European Medicines Agency, Genomics England, NICE, NHS England, NHS Scotland, NHS Wales, and the UK Genetic Testing Network.

Genetic Alliance UK was the only charity in our health sector to campaign to remain in the European Union, and members of our team spoke against Brexit before the referendum. Following the referendum, our team has participated in events and meetings to ensure the ultimate settlement is as positive as possible for families affected by genetic conditions.

**Research**

This year saw the end of the Treating Adrenal Insufficiency in Neonates (TAIN) project led by the University of Sheffield. Funded by the Framework Programme 7 grant from the European Commission, the Genetic Alliance UK team interviewed and surveyed parents of children with adrenal insufficiency, gaining insight into the wider impact of the condition, the challenges associated with parenting a child with a rare condition and the daily and critical treatment regime. The research highlighted unmet needs of families and helped identify areas for future research and opportunities to influence policy of benefit to patients.

The Hidden Costs project also finished this year, the findings of which demonstrated that the way health services are organised impacts negatively on families with rare genetic conditions, making life stressful and costly. This will be valuable evidence for decision makers and commissioners in the NHS as they plan service developments and support best practice.

**Support**

Our SWAN UK (syndromes without a name) support network entered its sixth year supported by a new Big Lottery Fund grant covering activity in England. The SWAN UK project receives funding from a range of sources including corporate and community donations which allows it to operate across the UK. The calendar year 2017 is the last year of
support from House of Fraser, who we would like to thank for their generosity which has had a huge impact in facilitating the growth of SWAN UK. We welcomed 382 new contacts across 216 families. We delivered 250 balloon bouquets to SWAN UK children in hospital as a token reminder of support from their friends in our network.

The fourth Undiagnosed Children’s Day was celebrated at the end of April, raising over £20,000 with events across the UK including a party at Birmingham Children’s Hospital Outpatients’ Department in partnership with Roald Dahl’s Marvellous Children’s Charity.
TREASURER’S LETTER AND FINANCIAL REVIEW

Thank you to all our members and funders who have helped to support the work we describe in this report.

Review of the financial position
The results for the year are set out in the statement of financial activities on page 17. Total income for the year was £1,048,394 compared to £861,043 in the previous year. This growth was primarily due to approximately £228,000 of income received last year and credited to restricted income in the current year. This reflects a change in our policy for this year (supported by the statement of recommended practice) of not deferring restricted income simply because related expenditure is planned to take place next in the following year.

Principal funding elements
Total expenditure for the year was £794,205 compared to £845,387. There was therefore a surplus of £254,189 in the year compared to a small surplus of £15,656 last year. £215,562 of the current year surplus has been reflected by increased project funds of £464,509 (last year £248,947) to be spent next year. Again this growth reflects the changed deferred income policy previously mentioned. General unrestricted funds increased in the year by £38,627 to £180,417.

Reserves policy
Unrestricted Reserves of £180,417 represents 5.3 months’ expenditure on total core costs of £409,174. Unrestricted costs of £140,680 in the statement of financial activities on page 17 are net of £268,944 of salaries and overheads charged to restricted projects in the year. If no projects were awarded to the charity, these salaries and overheads would still need to be paid. The trustees have set a target in the medium term to increase the level of unrestricted reserves to approximately nine months’ expenditure which would equal about £307,000. This will be achieved primarily by attracting more unrestricted donations to support the core objects of the charity, and the budgets going forward will reflect this.

Conclusion
In the coming financial year we will seek to diversify income sources for Genetic Alliance UK with the aim of ensuring sustainability to support our future activities.

Richard West
Treasurer
PLANS FOR FUTURE PERIODS

There are two key personnel changes for 2017–18. Jayne Spink PhD becomes Chief Executive of Genetic Alliance UK at the beginning of the year, taking over from Alastair Kent OBE who stands down as Director to take up a role as Ambassador. The management team position with responsibility for fundraising and income generation will also be filled. This is the perfect time to produce a new strategy for the organisation, which will be one of the key joint activities with our members for this year.

Our policy and public affairs work will focus on the continuing key issues of access to treatments; implementation of the UK Strategy for Rare Diseases; and exiting the European Union. We already have a strong network of collaborators and stakeholders in Europe, and over the coming year we will be working to ensure these relationships can continue following Britain’s exit from the European Union. As we approach the end of the 100,000 Genomes Project, we will be working to ensure that the legacy of the project benefits families affected by genetic conditions. The Rare Disease UK campaign will carry out a piece of work to examine the experience of children with rare diseases and their siblings. The campaign will also run a pilot to explore the complex relationship between mental health and rare conditions.

The SWAN UK support network will expand the proportion of the country covered by its Local Networks initiatives, and work to improve provision of support in Northern Ireland, Scotland and Wales. We will be increasing the number of information events that we run in new locations and will also be expanding the provision of resources, including making information available in community languages. There will be a focus on better support for fathers of children with undiagnosed genetic conditions and on increasing engagement in hard to reach communities.

New projects for the year will include:
- building on the work of the Hidden Costs project with a large-scale health economics project in collaboration with University College London and other partners.
- an examination of new born screening programme decision-making, examining the steps taken by UK National Screening Committee to approve a new programme.
- the Fresh Steps project in Scotland, developing a new toolkit for parents and carers of children with rare and undiagnosed genetic conditions focused on improving early intervention and prevention.
- a collaboration with Progress Educational Trust on communication of the new genome editing techniques and technologies, involving both of our stakeholder groups.
SWAN UK Parent Rep for Bristol, Louise James and her son Scotty at Hop Skip & Jump Bristol, a stay and play venue which SWAN UK hires for members every two months Photograph: Joey Beard
STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution
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.

Appointment and training 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 four times in the year ending 31 March 2017, where they determined and approved the strategy, operating plans and budget and reviewed the charity’s performance. Trustees delegate certain powers in connection with the charity’s management, remuneration (related to responsibility and market comparisons) and administration to the Finance and Governance (F&G) committee, which convened six times in the year.

The F&G committee comprises four trustees and the senior management team. 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 facilitate staff to achieve a high level of job satisfaction thereby enabling them to feel fulfilled, supported and provided with career development opportunities.

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 Board of Trustees’ Report and Accounts 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.

**Provision of information to auditors**

Each of the persons who are trustees at the time when this Report of the Board of Trustees and Accounts 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.

**Reelection of auditors**

In accordance with section 485 of the Companies Act 2006, a resolution 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.
REFERENCE AND ADMINISTRATIVE DETAILS

Company number
0577 2999

Registered charity numbers
1114 195 (England and Wales)
SC03 9299 (Scotland)

Registered office
Level 3, Barclay House
37 Queen Square
London, WC1N 3BH

020 7813 0883

Until 19 September 2016, Genetic Alliance UK ltd’s registered office was:
Unit 4d, Leroy House
436 Essex Road
London, N1 3QP

Trustees
Chris Goard*, Chair
Richard West*, Treasurer
Sally George
Dr Mike Knapton
John Mills
Tania Tirraoro*
Jenny Versnel (appointed 27 September 2016)
Susan Walsh (appointed 27 September 2016)
Dr Rafael Yanez*
* Member of the Finance and Governance Committee

Observers
Rebecca Griffiths
Caroline Harrison
Dr Fiona Hemsley
Fiona Macrae
Robin Nott
Dr Harriet Teare
Dr Lisa Walker
Jill Walton
Phyllis Wong
Nicole Yost

Company Secretary
Simon Evans

Director
Alastair Kent OBE (until 18 April 2017, Jayne Spink PhD took office as Chief Executive on 19 April 2017)

Management team
Buddug Cope (until 22 November 2016), Simon Evans (from 30 January 2017), Dr Amy Hunter, Nick Meade, Lauren Roberts, Stuart Watt FCCA (until 31 January 2017)

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

Nationwide Business Savings, PO Box 3, 5–11 St George’s Street, Douglas, Isle of Man, IM99 1AS

Virgin Money Saving, Jubilee House, Gosforth,
Newcastle upon Tyne, NE3 4PL

Website
geneticalliance.org.uk

Facebook
facebook.com/GeneticAllianceUK

Twitter
twitter.com/GeneticAll_UK
INDEPENDENT AUDITOR’S REPORT

to the members of Genetic Alliance UK

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2017 which comprise the statement of financial activities, the balance sheet, the cash flow statement and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the charitable 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 charitable company’s members those matters we are required to state to them in an auditors’ report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and its members, as a body, for our audit work, for this report, or for the opinion we have formed.

Respective responsibilities of trustees and auditors

As explained more fully in the trustees’ responsibilities statement, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view.

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

Our responsibility is to audit the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board’s Ethical Standards for Auditors.

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.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the company’s circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the trustees; and the overall presentation of the financial statements. In addition, we read all the financial and non-financial information in the Report of the Board of Trustees and Accounts to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of
any apparent material misstatements or inconsistencies we consider the implications for our report.

**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 2017 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of 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 matter prescribed by the Companies Act 2006**

In our opinion the information given in the Report of the Board of Trustees 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 and the Charities Accounts (Scotland) Regulations (as amended) 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 Report of the Board of Trustees and Accounts.

Jennifer Pope (senior statutory auditor)

for and on behalf of

Nyman Libson Paul

Chartered Accountants
Registered Auditors
Regina House, 124 Finchley Road, London, NW3 5JS
Date: 29 August 2017
# STATEMENT OF FINANCIAL ACTIVITIES
for the year ended 31 March 2017

<table>
<thead>
<tr>
<th>Note</th>
<th>Restricted funds</th>
<th>Unrestricted funds</th>
<th>Total funds</th>
<th>Total funds Restated</th>
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<td>Investments</td>
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<td>Charitable activities – Other</td>
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<td><strong>Total income</strong></td>
<td>869,087</td>
<td>179,307</td>
<td>1,048,394</td>
<td>861,043</td>
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<tr>
<td>Expenditure on:</td>
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<td>£</td>
<td>£</td>
<td>£</td>
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<tr>
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<td>39,372</td>
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<td>Charitable activities</td>
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<td>Information and Education</td>
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<td>64,685</td>
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<td><strong>Total expenditure</strong></td>
<td>6</td>
<td>653,525</td>
<td>140,680</td>
<td>794,205</td>
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<td><strong>Net income (expenditure)</strong></td>
<td>215,562</td>
<td>38,627</td>
<td>254,189</td>
<td>15,656</td>
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<td><strong>Net movement in funds</strong></td>
<td>215,562</td>
<td>38,627</td>
<td>254,189</td>
<td>15,656</td>
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<td><strong>Reconciliation of funds</strong></td>
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<td>£</td>
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<td>Total funds brought forward</td>
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<td><strong>Total funds carried forward</strong></td>
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<td>464,509</td>
<td>180,417</td>
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## BALANCE SHEET
for the year ended 31 March 2017

Genetic Alliance UK ltd. A company limited by guarantee.
Company number: 05772999.

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<th>Notes</th>
<th>2017</th>
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<td>Current assets</td>
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</tr>
<tr>
<td>Debtors, accrued income and prepayments</td>
<td>9</td>
<td>151,424</td>
</tr>
<tr>
<td>Cash at bank and in hand</td>
<td>607</td>
<td>597,381</td>
</tr>
<tr>
<td>Total current assets</td>
<td>748,805</td>
<td>769,241</td>
</tr>
<tr>
<td>Creditors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amounts due within one year</td>
<td>11</td>
<td>(103,879)</td>
</tr>
<tr>
<td>Net current assets</td>
<td></td>
<td>644,926</td>
</tr>
<tr>
<td>Total assets less current liabilities</td>
<td>644,926</td>
<td>390,737</td>
</tr>
<tr>
<td>The funds of the Charity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restricted funds</td>
<td>10</td>
<td>464,509</td>
</tr>
<tr>
<td>Unrestricted funds</td>
<td>10</td>
<td>180,417</td>
</tr>
<tr>
<td>Total charity funds</td>
<td>644,926</td>
<td>390,737</td>
</tr>
</tbody>
</table>

The financial statements were approved by the trustees on 29 August 2017 and signed on their behalf by:

Christopher Goard, Richard West,
Chair Honorary Treasurer

The notes on pages 19 to 27 form part of these financial statements.
CASH FLOW STATEMENT
for the year ended 31 March 2017

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash flows from operating activities</td>
<td>(67,669)</td>
<td>50,999</td>
</tr>
<tr>
<td>Cash flows from investing activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interest received</td>
<td>1,193</td>
<td>2,937</td>
</tr>
<tr>
<td>Change in cash and cash equivalents</td>
<td>(66,476)</td>
<td>53,936</td>
</tr>
<tr>
<td>at the beginning of the year</td>
<td>663,857</td>
<td>609,921</td>
</tr>
<tr>
<td>Total cash and cash equivalents</td>
<td>597,381</td>
<td>663,857</td>
</tr>
</tbody>
</table>

Reconciliation of net incoming resources to net cash flow from operating activities

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net income before other recognised</td>
<td>254,189</td>
<td>15,656</td>
</tr>
<tr>
<td>gains or losses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interest received</td>
<td>(1,193)</td>
<td>(2,937)</td>
</tr>
<tr>
<td>Decrease / (increase) in debtors</td>
<td>(46,040)</td>
<td>(39,550)</td>
</tr>
<tr>
<td>Increase / (decrease) in creditors</td>
<td>(274,625)</td>
<td>77,830</td>
</tr>
<tr>
<td>Net cash inflow from operating</td>
<td>(67,669)</td>
<td>50,999</td>
</tr>
<tr>
<td>activities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

NOTES TO THE FINANCIAL STATEMENTS
for the year ended 31 March 2017

1 Accounting policies

1.1 Basis of preparation of financial statements

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued on 16 July 2014 and the Charities Act 2011 and UK Generally Accepted Accounting Practice as it applies from 1 January 2015.

The financial statements have been prepared to give a ‘true and fair’ view and have departed from the Charities (Accounts and Reports) Regulations 2008 only to the extent required to give a ‘true and fair view’. This departure has involved following Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting in the UK and Republic of Ireland (FRS102) issued on 16 July 2014 rather than the Accounting and Reporting by Charities:

Statement of Recommended Practice effective from 1 April 2005 which has since been withdrawn.

Genetic Alliance UK meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note. No such restatement was required.

In preparing the accounts, the trustees have considered whether in applying the accounting policies required by FRS 102 and the Charities’ SORP FRS 102 the restatement of comparative items was required.

The trustees have reviewed the circumstances of the charity, and consider that adequate resources continue to be available to fund the activities of the charity for the foreseeable future. The trustees consider that there are no material uncertainties about the charity’s ability to continue as a going concern.
1.2 Income
All income is included in the statement of financial activities 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 when the money is due from the funder 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 Expenditure
Expenditure is charged to the statement of financial activities 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. For staff employed before January 2016, the charity contributes 7% of salary to the pension scheme when staff contribute 3% or more to it. For staff employed after December 2015, the charity contributes 5% 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 assets 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 unrealised exchange gain of £3,881 (2016 loss of £6,685) is recognised in these notes to 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 Corporation Taxes Act 1988.

1.10 Recognition of liabilities
Liabilities are recognised when there is a legal or constructive obligation that commits the Charity to the obligation.

1.11 Financial instruments
The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments, these are cash at bank, debtors and creditors (see notes 9 and 11). Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

1.12 Debtors, prepayments and accrued income
Debtors are trade and other debtors, recognised at the settlement amount due, prepayments are valued at the amount prepaid and accrued grant income is measured as the amount agreed with the grantor.

1.13 Creditors
Creditors are creditors and provisions, recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.
1.14 Significant estimates and judgements
The preparation of the financial statements requires management to make judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the reporting date and the amounts reported for revenues and expenses during the year. However, the nature of estimation means that actual outcomes could differ from those estimates.

1.15 Accruals
The company makes an estimate of accruals at the year end based on invoices received after the year end and work undertaken which has not been invoiced based on quotations or estimates of amounts that may be due for payment.

1.16 Tangible fixed assets
Fixtures and fittings are depreciated over their useful lives taking into account residual values where appropriate. The actual lives of the assets and residual values are assessed annually and may vary depending upon a number of factors. In re-assessing the assets’ lives, factors such as technological innovation, product life cycles and maintenance programmes are taken into account.

2 Donations and legacies

<table>
<thead>
<tr>
<th>Restricted funds 2017</th>
<th>Unrestricted funds 2017</th>
<th>Total funds 2017</th>
<th>Total funds 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>General donations to Rare Disease UK</td>
<td>15,125</td>
<td>15,125</td>
<td>10,822</td>
</tr>
<tr>
<td>General donations to SWAN UK</td>
<td>65,411</td>
<td>65,411</td>
<td>88,383</td>
</tr>
<tr>
<td>GlaxoSmithKline</td>
<td>40,000</td>
<td>40,000</td>
<td>40,000</td>
</tr>
<tr>
<td>House of Fraser</td>
<td>118,932</td>
<td>118,932</td>
<td>16,894</td>
</tr>
<tr>
<td>Thomas Cook</td>
<td>17,795</td>
<td>17,795</td>
<td></td>
</tr>
<tr>
<td>Legacy</td>
<td></td>
<td></td>
<td>75</td>
</tr>
<tr>
<td>Marsh</td>
<td>10,000</td>
<td>10,000</td>
<td>10,000</td>
</tr>
<tr>
<td>Medical Research Council</td>
<td>19,174</td>
<td>19,174</td>
<td>20,025</td>
</tr>
<tr>
<td>Membership subscriptions</td>
<td>44,659</td>
<td>44,659</td>
<td>15,276</td>
</tr>
<tr>
<td>Other donations</td>
<td>40,000</td>
<td>40,000</td>
<td>40,000</td>
</tr>
<tr>
<td>Wellcome Trust</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary income</td>
<td>217,263</td>
<td>153,833</td>
<td>371,096</td>
</tr>
</tbody>
</table>

3 Investment income

<table>
<thead>
<tr>
<th>Restricted funds 2017</th>
<th>Unrestricted Funds 2017</th>
<th>Total funds 2017</th>
<th>Total Funds 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interest receivable</td>
<td>0</td>
<td>1,193</td>
<td>1,193</td>
</tr>
</tbody>
</table>
### Charitable activities – grants receivable

<table>
<thead>
<tr>
<th>Activity</th>
<th>Restricted funds 2017</th>
<th>Unrestricted funds 2017</th>
<th>Total funds 2017</th>
<th>Total funds 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Medicines in England</td>
<td>-</td>
<td>-</td>
<td>5,000</td>
<td></td>
</tr>
<tr>
<td>Access to Medicines in England – dissemination</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to Medicines Scotland</td>
<td>17,435</td>
<td>17,435</td>
<td>27,565</td>
<td></td>
</tr>
<tr>
<td>Access to Medicines (Wales)</td>
<td>30,000</td>
<td>30,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accelerated Access Review Webinars</td>
<td>-</td>
<td>-</td>
<td>10,000</td>
<td></td>
</tr>
<tr>
<td>Animals in Research</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ATMP Workshops</td>
<td>-</td>
<td>-</td>
<td>24,216</td>
<td></td>
</tr>
<tr>
<td>Breaking Down Barriers</td>
<td>5,034</td>
<td>5,034</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empowerment Webinar</td>
<td>10,504</td>
<td>10,504</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EU Patients Academy (E.U.P.A.T.I)</td>
<td>124</td>
<td>124</td>
<td>24,675</td>
<td></td>
</tr>
<tr>
<td>Genetic Alliance UK in Scotland</td>
<td>-</td>
<td>-</td>
<td>31,000</td>
<td></td>
</tr>
<tr>
<td>Gen Equip –ERASMUS</td>
<td>5,923</td>
<td>5,923</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genome Editing</td>
<td>27,413</td>
<td>27,413</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genomics Conversation</td>
<td>25,980</td>
<td>25,980</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping patients help themselves : England</td>
<td>78,118</td>
<td>78,118</td>
<td>12,983</td>
<td></td>
</tr>
<tr>
<td>Helping patients help themselves : Scotland</td>
<td>8,063</td>
<td>8,063</td>
<td>14,439</td>
<td></td>
</tr>
<tr>
<td>(previously Supporting Patient Groups in Scotland)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping patients help themselves: Wales</td>
<td>-</td>
<td>-</td>
<td>4,712</td>
<td></td>
</tr>
<tr>
<td>Hidden Cost of Rare Diseases</td>
<td>37,200</td>
<td>37,200</td>
<td>25,670</td>
<td></td>
</tr>
<tr>
<td>Insurance and Genetics – UKFGI</td>
<td>33,384</td>
<td>33,384</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My Cancer, My DNA</td>
<td>-</td>
<td>-</td>
<td>55,370</td>
<td></td>
</tr>
<tr>
<td>My Condition, My DNA</td>
<td>-</td>
<td>-</td>
<td>1,018</td>
<td></td>
</tr>
<tr>
<td>Neuro-enhancement: Responsible Research and Innovation</td>
<td>14,578</td>
<td>14,578</td>
<td>24,656</td>
<td></td>
</tr>
<tr>
<td>Producing Effective Patient Leaflets -P.H.E.</td>
<td>5,598</td>
<td>5,598</td>
<td></td>
<td></td>
</tr>
<tr>
<td>R.A.P.I.D.: Patient Experiences</td>
<td>-</td>
<td>-</td>
<td>1,868</td>
<td></td>
</tr>
<tr>
<td>Rare Disease UK</td>
<td>219,046</td>
<td>219,046</td>
<td>149,199</td>
<td></td>
</tr>
<tr>
<td>SWAN UK: England</td>
<td>- 96</td>
<td>- 96</td>
<td>71,444</td>
<td></td>
</tr>
<tr>
<td>SWAN UK: BLF England</td>
<td>104,703</td>
<td>104,703</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK: Family Fun Days</td>
<td>- 3,663</td>
<td>- 3,663</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK: Local Networks</td>
<td>5,878</td>
<td>5,878</td>
<td>89,919</td>
<td></td>
</tr>
<tr>
<td>T.A.I.N: Patient Experiences</td>
<td>7,516</td>
<td>7,516</td>
<td>14,890</td>
<td></td>
</tr>
<tr>
<td>T.A.I.N 2 AID</td>
<td>19,086</td>
<td>19,086</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total: 651,824

### Charitable Activities – Other Income

<table>
<thead>
<tr>
<th>Activity</th>
<th>Restricted funds</th>
<th>Unrestricted funds</th>
<th>Total funds</th>
</tr>
</thead>
<tbody>
<tr>
<td>HFEA – Net Contribution</td>
<td>10,195</td>
<td>10,195</td>
<td>15,363</td>
</tr>
<tr>
<td>Conference and Other Receipts</td>
<td>14,086</td>
<td>14,086</td>
<td>9,917</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>25,280</td>
</tr>
</tbody>
</table>
6  Total Expenditure

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

<table>
<thead>
<tr>
<th>Costs directly allocated to activities</th>
<th>Basis of allocation</th>
<th>Membership and fundraising</th>
<th>Information and education</th>
<th>Governance</th>
<th>Restricted funds</th>
<th>Total 2017</th>
<th>Total 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific project work</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff costs</td>
<td>Direct</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>314,035</td>
<td>314,035</td>
</tr>
<tr>
<td>Consultancy and professional fees</td>
<td>Direct</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>19,910</td>
<td>19,910</td>
</tr>
<tr>
<td>Conferences and events</td>
<td>Direct</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>39,327</td>
<td>39,327</td>
</tr>
<tr>
<td>Travel and subsistence</td>
<td>Direct</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>34,804</td>
<td>34,804</td>
</tr>
<tr>
<td>Website</td>
<td>Direct</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3,848</td>
<td>3,848</td>
</tr>
<tr>
<td>Other attributable costs</td>
<td>Direct</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>48,567</td>
<td>48,567</td>
</tr>
</tbody>
</table>

| Support costs in relation to activities|                     |                            |                           |            |                 |            |            |
| Staff costs                            | Staff time          | 47,871                     | 100,827                   | 26,517     | 44,423          | 219,638    | 177,438    |
| Occupancy and administration costs     | Allocation          | (14,207)                   | (14,207)                  | (14,207)   | 148,611         | 105,990    | 120,007    |
| Travel and Subsistence                 | Allocation          |                            |                           |            | 2,486           | 2,486      | 2,529      |
| Legal and professional fees            | Direct              |                            |                           |            |                 | -          | -          |
| Audit and accountancy fee              | Direct              |                            |                           |            | 5,600           | 5,600      | 5,760      |
| Allocation of Governance Costs         | Direct              | 5,708                      | 14,688                    | (20,396)   |                 | -          | -          |

Total 39,372 101,308 - 653,525 794,205 845,387

7  Trustees’ benefits: advances, credit and guarantees

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

Trustees were reimbursed a total of £2,486 (2016: £2,259) in respect of travelling expenses.

£263 (2016 £263) was paid in respect of a trustee indemnity policy.
8 Analysis of Staff Costs and the Cost of Key Management Personnel

The average number of employees during the year was:

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14.7</td>
<td>15</td>
</tr>
</tbody>
</table>

The following table shows the breakdown of total staff costs and related expenses for the year ended 30th June 2017 and 2016:

- **Total Staff Costs**
  - Wages and salaries: £466,905 (2016: £493,946)
  - Social security costs: £35,218 (2016: £46,631)
  - Pension costs: £31,548 (2016: £13,563)
  - Interim Costs: £2,000 (2016: £535,671, 2016: £554,140)

One employee earned more than £60,000.

During the year the charity made pension contributions in respect of 15 employees (2016: 5).

The following table shows the breakdown of the cost of key management personnel:

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Wages and salaries</td>
<td>159,996</td>
<td>159,124</td>
</tr>
<tr>
<td>Social security costs</td>
<td>17,881</td>
<td>17,575</td>
</tr>
<tr>
<td>Pension costs</td>
<td>11,166</td>
<td>11,139</td>
</tr>
<tr>
<td>Interim Costs</td>
<td>2,000</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Cost of key management personnel</strong></td>
<td>191,043</td>
<td>187,838</td>
</tr>
</tbody>
</table>

The key management personnel are the Chief Executive, the Director of Policy, the Director of Research, the Director of Support and the Director of Finance.

9 Debtors

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£</td>
<td>£</td>
</tr>
<tr>
<td>Trade debtors</td>
<td>37,200</td>
<td>26,020</td>
</tr>
<tr>
<td>Other debtors</td>
<td>15,036</td>
<td>-</td>
</tr>
<tr>
<td>Prepayment and accrued income</td>
<td>99,188</td>
<td>79,364</td>
</tr>
<tr>
<td><strong>Total Debtors</strong></td>
<td>151,424</td>
<td>105,384</td>
</tr>
</tbody>
</table>
10 Statement of funds

<table>
<thead>
<tr>
<th>unrestricted funds</th>
<th>brought forward (£)</th>
<th>incoming resources (£)</th>
<th>less resource expended (£)</th>
<th>transfers in / (out) (£)</th>
<th>carried forward (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General funds – all funds</td>
<td>141,790</td>
<td>179,307</td>
<td>140,680</td>
<td>180,417</td>
<td></td>
</tr>
</tbody>
</table>

### restricted funds

<table>
<thead>
<tr>
<th>fund category</th>
<th>project</th>
<th>brought forward (£)</th>
<th>incoming resources (£)</th>
<th>less resource expended (£)</th>
<th>transfers in / (out) (£)</th>
<th>carried forward (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accelerated Access Reviews Webinars</td>
<td>562</td>
<td>-</td>
<td>562</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to Medicines (Wales)</td>
<td>30,000</td>
<td>9,400</td>
<td>20,600</td>
<td></td>
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<tr>
<td>Access to Medicines in England</td>
<td>12,428</td>
<td>-</td>
<td>3,947</td>
<td>8,481</td>
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<tr>
<td>Access to Medicines Scotland</td>
<td>2,098</td>
<td>17,435</td>
<td>18,112</td>
<td>1,421</td>
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<tr>
<td>Animals in Research</td>
<td>8,800</td>
<td>-</td>
<td>-</td>
<td>8,800</td>
<td></td>
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<tr>
<td>ATMP Workshops</td>
<td>7,853</td>
<td>-</td>
<td>3,494</td>
<td>4,359</td>
<td></td>
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<tr>
<td>Breaking Down Barriers</td>
<td>5,034</td>
<td>-</td>
<td>-</td>
<td>5,034</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empowerment Webinar</td>
<td>-</td>
<td>10,504</td>
<td>-</td>
<td>10,504</td>
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<tr>
<td>EU Patients Academy (E.U.P.A.T.I)</td>
<td>-</td>
<td>124</td>
<td>124</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gen Equip - ERASMUS</td>
<td>5,923</td>
<td>40</td>
<td>-</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genome Editing</td>
<td>27,413</td>
<td>14,688</td>
<td>12,725</td>
<td>-</td>
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<tr>
<td>Genomics Conversation</td>
<td>25,980</td>
<td>19,013</td>
<td>-</td>
<td>6,967</td>
<td></td>
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<tr>
<td>Helping patients help themselves: Wales</td>
<td>4,309</td>
<td>-</td>
<td>2,096</td>
<td>2,213</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping patients help themselves: England</td>
<td>2,540</td>
<td>78,118</td>
<td>31,685</td>
<td>48,973</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping patients help themselves: Scotland (previously Supporting Patient Groups in Scotland)</td>
<td>13,674</td>
<td>8,063</td>
<td>12,664</td>
<td>9,073</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hidden Cost of Rare Diseases</td>
<td>1,885</td>
<td>37,200</td>
<td>40,433</td>
<td>(1,348)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance and Genetics – UKFGI</td>
<td>-</td>
<td>33,384</td>
<td>-</td>
<td>33,384</td>
<td></td>
<td></td>
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<tr>
<td>MS Research in Scotland</td>
<td>2,745</td>
<td>-</td>
<td>-</td>
<td>2,745</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My Condition, My DNA</td>
<td>1,016</td>
<td>-</td>
<td>860</td>
<td>156</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuro-enhancement: Responsible Research and Innovation</td>
<td>-</td>
<td>14,578</td>
<td>14,595</td>
<td>(17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Engagement in Scotland</td>
<td>5,111</td>
<td>-</td>
<td>29</td>
<td>5,582</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Producing Effective Patient Leaflets - P.H.E.</td>
<td>-</td>
<td>5,598</td>
<td>-</td>
<td>5,598</td>
<td></td>
<td></td>
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<tr>
<td>Rare Disease UK General Donations</td>
<td>14,321</td>
<td>15,125</td>
<td>1,204</td>
<td>28,242</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rare Disease UK</td>
<td>9,071</td>
<td>219,046</td>
<td>203,211</td>
<td>24,906</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK: Northern Ireland Information Event</td>
<td>631</td>
<td>-</td>
<td>-</td>
<td>631</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK Family Events 2016 Thomas Cook</td>
<td>-</td>
<td>17,795</td>
<td>12,471</td>
<td>5,324</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK: BLF England</td>
<td>104,703</td>
<td>74,090</td>
<td>70,539</td>
<td>30,613</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK: House of Fraser Events 2016</td>
<td>13,989</td>
<td>50,681</td>
<td>46,465</td>
<td>205</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK: House of Fraser Events 2017</td>
<td>13,989</td>
<td>68,250</td>
<td>64,465</td>
<td>205</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWAN UK: Local Networks</td>
<td>16,622</td>
<td>5,878</td>
<td>22,500</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWANUK: Family Fun Days</td>
<td>4,170</td>
<td>(3,663)</td>
<td>507</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T.A.I.N 2 AISD</td>
<td>19,086</td>
<td>16,454</td>
<td>2,632</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>T.A.I.N: Patient Experiences</td>
<td>1,167</td>
<td>7,516</td>
<td>3,850</td>
<td>4,833</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total of funds | 390,737 | 1,048,394 | 794,205 | - | 644,926 |
Each fund is for a specific project for which Genetic Alliance UK receives a restricted grant or donation.

Summary of funds

<table>
<thead>
<tr>
<th></th>
<th>Brought forward</th>
<th>Incoming resources</th>
<th>Resources expended</th>
<th>Transfers in/(out)</th>
<th>Carried forward</th>
</tr>
</thead>
<tbody>
<tr>
<td>General funds</td>
<td>£141,790</td>
<td>£179,307</td>
<td>£140,680</td>
<td>£180,417</td>
<td></td>
</tr>
<tr>
<td>Restricted funds</td>
<td>£248,947</td>
<td>£869,087</td>
<td>£653,525</td>
<td></td>
<td>£464,509</td>
</tr>
<tr>
<td></td>
<td>£390,737</td>
<td>£1,048,394</td>
<td>£794,205</td>
<td>-</td>
<td>£644,926</td>
</tr>
</tbody>
</table>

11 Creditors

<table>
<thead>
<tr>
<th></th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trade creditors and accruals</td>
<td>£82,264</td>
<td>£137,954</td>
</tr>
<tr>
<td>Other creditors</td>
<td>£15,124</td>
<td>£5,821</td>
</tr>
<tr>
<td>Deferred income</td>
<td>£6,491</td>
<td>£234,729</td>
</tr>
<tr>
<td></td>
<td>£103,879</td>
<td>£378,504</td>
</tr>
</tbody>
</table>

12 Analysis of net assets between funds

<table>
<thead>
<tr>
<th></th>
<th>Restricted funds 2017</th>
<th>Unrestricted funds 2017</th>
<th>Total funds 2017</th>
<th>Total funds 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current assets</td>
<td>£495,419</td>
<td>£253,386</td>
<td>£748,805</td>
<td>£769,241</td>
</tr>
<tr>
<td>Creditors due within one year</td>
<td>(30,910)</td>
<td>(72,969)</td>
<td>(103,879)</td>
<td>(378,504)</td>
</tr>
<tr>
<td></td>
<td>£464,509</td>
<td>£180,417</td>
<td>£644,926</td>
<td>£390,737</td>
</tr>
</tbody>
</table>

13 Operating lease commitments

At 31 March 2017 the charity had future minimum lease payments under non-cancellable operating leases as follows:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Buildings</td>
<td>£</td>
<td>Buildings</td>
<td>£</td>
</tr>
<tr>
<td>Later than one year</td>
<td></td>
<td>16,386</td>
<td>557</td>
<td>378</td>
</tr>
<tr>
<td>Later than one year and not later than five years</td>
<td>36,000</td>
<td>9,000</td>
<td>2,785</td>
<td></td>
</tr>
<tr>
<td>Later than five years</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>36,000</td>
<td>16,386</td>
<td>9,557</td>
<td>3,163</td>
</tr>
</tbody>
</table>
14 Related party transactions
There were no related party transactions in the year.

This report was approved by the trustees on 29 August 2017 and signed on their behalf by:

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

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. We would like to particularly thank:

- Our trustees and observers, who bring invaluable commitment and knowledge to our Board of Trustees.
- The sixteen parent representatives who work with the project team to help provide local support through the SWAN UK Local Networks.
- The many members of Genetic Alliance UK and SWAN UK, and the supporters of the Rare Disease UK campaign, who have made our projects and events a success. We have held many public events throughout the year and are always grateful for the energy and enthusiasm of members who attend or support the events in other ways. In particular, a number of patients and carers have contributed as speakers at our events providing unique personal insights that bring 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, families and schools 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
- AKCEA ²
- Alexion ³
- Amgen ⁴
- Amicus Therapeutics ⁵
- Awards for All ⁶
- Baxalta ⁷
- BC Partners Foundation ⁸
- Big Lottery Fund ⁹
- Bio Marín ¹⁰
- Chiesi ¹¹
- CSL Behring ¹²
- Diurnal ¹³
- Ernst & Young Cambridge Community Fund ¹⁴
- EU Commission – Erasmus+ ¹⁵
- EU Commission – FP7 Health ¹⁶
- EU Commission – FP7 Science in Society ¹⁷
- Galton Institute ¹⁸
- Genetics Society ¹⁹
- Genomics England ltd ²⁰
- Genzyme Sanofi ²¹
- GlaxoSmithKline ²²
- Healx ²³
- Horizon ²⁴
- House of Fraser ²⁵
- Human Fertilisation and Embryology Authority Innovative Medicines Initiative ²⁶
- Insurance With ²⁷
- John Ellerman Foundation ²⁸
- Kyowakirin ²⁹
- Law Firm Services ³⁰
- Leadiant Biosciences ltd ³¹
- Medical Research Council
- Merck ³²
- Novartis ³³
- Orchard ³⁴
Pfizer
PTC Therapeutics
Public Health England
Pycko Scientific Ltd
Raptor
Roche
Santhera
Scottish Government Section 16B
Shire
SOBI
Starbucks Red Cup Cheer
Sylvia Adams Charitable Trust
The Hospital Saturday Fund
Thomas Cook
UCB
UKFGI
Vertex
Wellcome Trust

The superscript numbers above refer to the funds listed on pages 21 and 22 in notes 2, 4, 5 to the accounts.

**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 Industries (for meeting space)
- Google (provision of G-Suite for non-profits)
- Medical Research Council (for meeting space)
- Royal College of Paediatrics and Child Health (for meeting space)
- Salesforce (provision of 10 free licences for non-profits)
- Tuberous Sclerosis Association (for meeting space)

**OUR MEMBERS**

- The 22 Crew
- The Aarskog Foundation
- Action Duchenne
- Action for Sick Children (Scotland)
- Action on Gilbert’s Syndrome
- Adrenal Hyperplasia Network
- Advocacy for Neuroacanthocytosis Patients
- aHUS UK
- Albinism Fellowship
- ALD LIFE
- Alkaptonuria Society
- Alpha 1 Alliance
- Alpha 1 Awareness UK
- Alport UK
- Alström Syndrome UK
- Aniridia Network UK
- Annabelle’s Challenge
- Anorchidism Support Group (ASG)
- Antenatal Results and Choices
- Archangel MLD Trust
- The Arthrogryposis Group (TAG)
- Assert
- Association for Glycogen Storage Diseases UK
- Ataxia UK
- Baby James’ Starlight Trust
- Bardet-Biedl Syndrome UK
- Barth Syndrome Trust
- Batten Disease Family Association
- Beckwith-Wiedemann Support Group
- Behcets Syndrome Society
- BRCA Umbrella
- Breathtakers Charity
- British Heart Foundation
- The British Porphyria Association
- The Brittle Bone Society
- Cambridge and East Anglia RP
- Cancer Research and Genetics UK
- Cardiomyopathy UK
- The Cavan Tommy Hoey Trust (Ireland)
- Cavernoma Alliance UK
- CDLS Foundation UK and Ireland
- Cerebrospinal Fluid Leak Association
CGD Society
CHAMP1 Patient Support Group
Child Growth Foundation
ChILd Lung Foundation
Children’s Mitochondrial Disease Network
Chromosome 18 Registry and Research Society (Europe)
Climb
CML Support Group
CMT United Kingdom
The Cogent Trust
Cohen Syndrome Support Group
Confer Scotland
Congenital Adrenal Hyperplasia Support Group
Costello Support Group (International)
Cri Du Chat Syndrome Support Group
Cure and Action Tay Sachs Foundation
Cystic Fibrosis Trust
DC Action
DDD/C3G Renal Support Group UK
DEBRA UK
Dercum’s Disease and Rare Disease Foundation UK
Diamond Blackfan Anaemia Support Group UK
Down’s Heart Group
Dyskeratosis Congenita Society
East London Branch Sickle Cell Society
Ectodermal Dysplasia Society
Ehlers-Danlos Support UK
Elijah’s Hope CIC
Fanconi Hope
FAP Gene Support Group
The Fragile X Society
Friends of Kabuki Syndrome
The Frontotemporal Dementia Support Group
FSH Muscular Dystrophy Support Group
Fuchsfriends UK
GATA2 Deficiency Support Group
The Gauchers Association
Genetic outreach project, funded by East Lancashire CCG, hosted by Home-start
The George Pantziarka TP53 Trust
GIST Support UK
Gorlin Syndrome Group
HAE UK
The Haemochromatosis Society
Haemophilia Society
HITS Worldwide
HME Support Group
HNPP
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 Syndrome Association
Hypermobility UK
Hypopara UK
Ichthyosis Support Group
IIH UK
The Information Point for Centronuclear and Myotubular Myopathy
Inherited Prion Disease Support Group
International Autistic Research Organisation
Jeune Syndrome Foundation
Jnetics
Keratoconus Self Help and Support Group
Klinefelter Organisation (UK)
Klinefelter’s Syndrome Association
Lily Foundation
Lipodystrophy UK
The Lowe Syndrome Trust
LPLD Alliance
Lynch Syndrome UK
Make Billy Smile
Making it Better – The Daniel Courtney Trust
Manchester Sickle Cell and Thalassaemia Centre
Marfan Association UK
Max Appeal
MEBO Research
Medical Advisory Service
Mike Matters
Moebius Research Trust
Mosaic Down Syndrome UK
Motor Neurone Disease Association
Mowat-Wilson Syndrome Support Group
MPGN/DDD Support Group
Muscular Dystrophy UK
Myotonic Dystrophy Support Group
Naitbabies.org
Narcolepsy UK
National Sickle Cell Programme
National Voices  
Nemaline Myopathy  
Nephrotic Syndrome Trust  
Neurofibromatosis Association (Neuro Foundation)  
Niemann-Pick Disease Group (UK)  
Noonan Syndrome Association  
Noonan UK  
NSPKU (UK) Ltd  
Organisation for Fetal Anti-Convulsant Syndromes  
OSCAR  
Osteopetrosis Support Trust  
Pemphigus Vulgaris Network  
Pennine Lancashire Genetics Outreach Project  
Peutz Jeghers Syndrome Support Group  
PID UK (Genetic Disorders UK)  
Plagiocephaly Care UK  
PNH Support Group  
Polycystic Kidney Disease Charity  
Prader Willi Syndrome Association UK  
Primary Ciliary Dyskinesia Family Support Group  
PSC Support Group  
PTEN UK & Ireland Patient Group  
PXE Support Group  
Rare Dementia Support  
Reverse Rett  
Ring20 Research & Support UK  
Royal Society for Blind Children  
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  
Sickle Cell Society  
SILA  
Society for Mucopolysaccharide Diseases  
SOFT UK  
SPARKS  
Special Needs Jungle  
Spinal Muscular Atrophy Support UK  
Stickler Syndrome Support Group  
Stiff Person Syndrome  
Tar Support Group  
Telangiectasia Self Help Group  
Thalidomide Society  
Thyroid UK  
TMAU  
TRPS Support Group UK  
Tuberous Sclerosis Association  
Turner Syndrome Support Society (UK)  
UK LGLL (UK Large granular lymphocyte leukaemia)  
The UK Mastocysts Support Group  
UK Potsies  
UK Thalassaemia Society  
UKPIPS  
Unique – The Rare Chromosome Disorder Support Group  
Usher Service – SENSE  
Vasculitis UK (SSVT)  
VHL UK/Ireland  
Williams Syndrome Foundation Limited  
Wilson’s Disease Support Group UK  
Worster Drought Syndrome Support Group  
XLP Research Trust  
XP Support Group
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 190 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. geneticalliance.org.uk

Rare Disease UK is the national campaign for people with rare diseases and all who support them. The campaign works with health departments across the UK to implement the UK Strategy for Rare Diseases to ensure that patients and families living with rare conditions have equitable access to high quality services, treatment and support. Rare Disease UK is run by Genetic Alliance UK. raredisease.org.uk

SWAN UK (syndromes without a name) is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. SWAN UK’s Big Ambition is that all families who have a child affected by a syndrome without a name get the support they need, when they need it. SWAN UK is run by Genetic Alliance UK. undiagnosed.org.uk