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GENETIC ALLIANCE UK

Financial statements for the year ended 31 March 2024

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Report of the Trustees

For the year ended 31 March 2024

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statement of the charity for the year ended 31 March 2024.

The Trustees have adopted the provision of 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) (effective 1 January 2019).

Background

Genetic Alliance UK is an alliance of over 200 charities and support groups. We have a thirty-year track record of working together to improve the lives of people in the UK living with lifelong and complex genetic and rare conditions.

Genetic and rare conditions in numbers

- Rare conditions are individually rare but collectively common, with over 3.5 million people in the UK living with a rare condition
- A rare condition is a condition that affects fewer than one in 2,000 people
- There are around 7,000 rare conditions, with new conditions regularly identified through scientific progress
- One in 17 people are affected by a rare condition at some point in their lives
- Seven in 10 rare conditions affect children
- More than 3 out of 10 children with a rare condition die before their fifth birthday

People living with genetic and rare conditions and their families face a lifetime of complex care. They need vital support from the NHS, social care and education services to live their lives to the full.

Summary of Annual Performance 2024

During 2023/24 Genetic Alliance UK continued to deliver on our strategic priorities:

1. Growing our alliance and supporting our members
2. Championing timely diagnosis and coordinated care for people living with rare conditions
3. Providing a strong voice for people living with genetic and rare conditions
4. Ensuring scientific breakthroughs in genomics drive better research and services
5. Promoting opportunities to expand screening in line with international best practice

Objectives and aims

Genetic Alliance UK is an alliance of over 200 charities and support groups working together to improve the lives of people living with genetic and rare conditions.

The objectives of the charity are to:

- Relieve persons affected by a genetic, and/or rare, and/or undiagnosed conditions;
- Advance the education of the public concerning genetic, and/or rare, and/or undiagnosed conditions in such ways as the trustees of the charity see fit.

We run two long-standing projects:

- Rare Disease UK, a campaign focused on making sure the new UK Rare Diseases Framework is as successful as possible. Rare Disease UK is the official UK organiser of Rare Disease Day.
- SWAN UK, the only dedicated support network in the UK for families affected by a syndrome without a name, a genetic condition so rare that it often goes undiagnosed.

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 2021 when reviewing the charity's aims and objectives and in implementing current and future planning activities.

During 2023/24 we developed a [new five-year strategy](#) for 2024-2029 setting out how our alliance will work together to improve the lives of 3.5 million people in the UK affected by lifelong and complex genetic and rare conditions.

Our purpose (why our alliance exists) is to work together to improve the lives of 3.5 million people in the UK living with lifelong and complex genetic and rare conditions.

Our aim (what we will do) is to make sure the ambitions in the UK Rare Disease Framework that matter most to people living with genetic and rare conditions drive action across the four nations.

Our objectives (how we will do it) are:

- Influencing national policy and provision where it matters most by:
 - Championing timely diagnosis and better coordinated care and treatment for people living with genetic and rare conditions.
 - Making sure an understanding of what is most important to people living with genetic and rare conditions shapes research, policy, regulation, practice and the development of new medicines and therapies.
 - Ensuring scientific breakthroughs in genomics reach people living with genetic conditions in a timely fashion through research programmes and routine diagnostic and clinical services.
 - Promoting opportunities to expand newborn and population screening for genetic and rare conditions in line with international best practice.
- Making sure our influencing drives action across both policy and practice.

- Tracking how people with genetic and rare conditions are affected by this action across the four nations.

Our critical success factors (how we are going to get there) are:

- Building a robust, resilient and flourishing alliance in terms of members, income, staff and trustees.
- Working collaboratively with key stakeholders such as umbrella groups for genetic and rare conditions, healthcare professional bodies and industry.
- Developing an effective influencing strategy to drive action related to the ambitions in the UK Rare Disease Framework that matter most.
- Monitoring and evaluating implementation of the UK Rare Disease Framework.

Our enablers (the things that will make it possible) to deliver this strategy are:

- Putting our members and the people living with genetic and rare conditions they support at the heart of everything we do: listening to their experience, learning from their expertise, helping members share knowledge with each other, and ensuring our voices are stronger when we work together.
- Professionalising our approach to membership, income generation, corporate services and communications.
- Building on the strengths of our well-regarded policy and research teams.
- Investing in our staff and supporting their training and development.
- Recruiting and retaining trustees with the skills, knowledge and diverse perspectives needed to scrutinise and shape our work.

Our values (the things we believe are important) are to be people-centred, collaborative, inclusive, influential, evidence-led, knowledge-generating and independent.

The development of our five-year strategy for 2024 to 2029 involved consultation with members, supporters and funders. The strategy was launched at the charity's Annual General Meeting in Autumn 2023. Each financial year we will develop a business plan and budget setting out our work for the coming year based on the aims and objectives in our strategy.

1. Growing our alliance and supporting our members

Building a growing and diverse alliance

During 2022/23 our membership increased. Our members range in size from a small number of household names like the Cystic Fibrosis Trust and DEBRA, through to a large number of specialist support groups led by parents of children with rare conditions, and affected adults, volunteering alongside their caring and work responsibilities. We believe our voices are stronger when we work together. We keep membership fees as low as possible to maximise the number of organisations working together to improve the lives of people living with genetic and rare conditions.

New members and improved opportunities for engagement

We welcomed 19 new member organisations into Genetic Alliance UK during 2023/24. These are:

ACTA2 Alliance
Arthur's Quest
Cure DHDDS
CUREUsher
The Down's Syndrome Association
The Epilepsy Society
FAR - Foundation for ARID1B Research
The Gary Woodward Dyskeratosis Congenita Trust
Galactosaemia Support Group
GRACE Project
Little Hearts Matter
Myaware
The Neurological Alliance
Pallister-Killian Syndrome UK (PKSUK)
PCD Research - Primary Ciliary Dyskinesia
Rareminds
RareQoL Ltd
Retina UK
Thrombosis UK

During 2023/24 we held 12 monthly Member Briefings to which we invited senior stakeholders to speak directly to our member charities and support groups. Member Briefings were well-attended with over 150 individuals joining at least one briefing and an average of 24 people attending each session.

We also held 12 monthly Member Brews where we bring our members together in a closed session to discuss common challenges and opportunities and share learning with one another. Member Brews were a popular way for members to work together, with over 100 individuals joining at least one brew and an average of 19 people attending each session.

Every month we are creating more opportunities for member organisations to amplify their voice and extend their reach. Examples include presentation slots at Member Briefings and Member Brews, increased promotion of awareness days and weeks, and improved engagement through social media channels and member communities.

Our new Genetic Alliance UK member social media takeovers were a huge success with over 20 member organisations taking part. We also hosted 39 takeovers on our Rare Disease UK Instagram, helping to increase the online reach of our members and individuals living with rare, genetic and undiagnosed conditions in the wider community.

Our new website

In 2020, Genetic Alliance UK carried out the Rare Experience survey to better understand the experiences and preferences of people affected by rare conditions. This survey highlighted the need for timely signposting to relevant patient organisations, as well as the need for easy to access relevant information from a credible source.

In 2023/24 we launched a new website to help our members meet these challenges. We have been working hard to turn geneticalliance.org.uk into a leading information and signposting hub for the UK's rare disease community, which will help raise awareness of our members and their amazing work, whilst also making it easier for the community to access relevant and credible information.

The new website will enable prospective members to join Genetic Alliance UK, engage with our resources and sign up to attend our virtual member meetings. It will also signpost our members to wider sources of reliable specialist support for the rare and genetic conditions sector in the UK, and make it easier for our members, industry partners and policy-makers to find our extensive library of policy reports and research papers on issues of shared concern for the sector.

We launched our new website in February 2024 thanks to the generous support of our industry partners. We continue to add updates, information resources and new content to benefit our members, stakeholders and the wider community.

2. Championing timely diagnosis and coordinated care for people living with rare conditions

Driving progress on UK Rare Diseases Framework

The UK Rare Diseases Framework was published in January 2021. This document outlines the governments' priorities for improving care for people living with rare conditions to be implemented over five years (2021-2026). In 2023/24 Genetic Alliance UK continued to work with its members to support the delivery of the UK Rare Diseases Framework and action plans. The Genetic Alliance UK team holds positions across the delivery groups responsible for the Framework and has been recognised in three of the four action plans for our role in their delivery. Our Rare Disease UK Patient Empowerment Group Recommendations Paper has been considered in meetings of all four nations in the development and implementation of their action plans.

In England, we worked with the Department of Health and Social Care to re-establish the England Rare Disease Action Plan Patient Advisory Group which directly fed into the development of the 2024 Action Plan. In Scotland, we are responsible for supporting the Scottish Government's patient involvement work for the Scottish Rare Disease Action Plan. In Wales, we sit on the Rare Disease Implementation Network (RDIN) which has responsibility for implementing the Welsh Rare Disease Action Plan and recently joined the newly established RDIN Leadership Group.

Working in partnership to deliver the Rare Disease Research UK Platform

A major new £14 million investment by the National Institute of Health Research (NIHR) and Medical Research Council (MRC) into rare condition research launched in 2023. They have invested in 11 'nodes' addressing different challenges - some are focused on groups of conditions or disease 'pathways', while others are cross-cutting such as developing innovative trial design to take account of small populations and to reduce trial costs. A coordinating 'hub' function, led by Newcastle University in partnership with Genetic Alliance UK and The Newcastle upon Tyne Hospitals NHS Foundation Trust, will support the nodes to achieve impact from their work and promote good practice in involving people with lived experience.

Additionally, Genetic Alliance UK is providing direct support to two of the nodes, to facilitate the involvement of people with lived experience: CAPTIVATE (focussed on innovative trial design) and UPNAT (progressing the development of a new class of therapies for rare genetic conditions).

Maximising opportunities to raise awareness on Rare Disease Day 2024

This year was a leap year so Rare Disease Day fell on 29 February, a date originally chosen for the annual international awareness day due to its rarity. On Thursday 29 February 2024 Rare Disease Day was celebrated in over 85 countries to raise awareness and generate change for the 300 million people worldwide living with a rare condition, and their families and carers.

Every year the theme is chosen by EURORDIS – Rare Diseases Europe, in collaboration with their patient organisation members. As the official organiser of Rare Disease Day in the UK through our campaign Rare Disease UK, Genetic Alliance UK coordinated closely with EURORDIS, our member organisations and relevant stakeholders to deliver a wide range of activities to express our international solidarity and highlight the priorities of the UK's rare community.

Central source of data about rare conditions

On Rare Disease Day 2024 we raised awareness of facts and figures about rare diseases in the UK with NHS staff, healthcare professionals, people living with rare disease and the public. We developed and published a central source of data about rare conditions in the UK which is hosted on the new Genetic Alliance UK website at geneticalliance.org.uk/campaigns-and-research/facts-and-figures/. These facts and figures provide an easy and impactful way to raise awareness and understanding of the challenges of living with a rare, genetic or undiagnosed condition in the UK.

Policy report to drive better understanding of data

Our [Stats Behind the Stories policy report](#) argues that we need to segment and better understand UK data about who has rare conditions, and which rare conditions they have, so that the NHS can provide the right services and support. The report includes case studies from Hereditary Brain Aneurysm Support, Superficial Siderosis Research Alliance, Better Together for Healthy Marrow Alliance and the Neurological Alliance to bring a human face to the facts and figures discussed in it. We would like to thank the member organisations who shared these vital stories with us.

Dissemination of the report has been a key focus since Rare Disease Day. We have met with the England Rare Disease Action Plan Delivery Group, the UK Rare Disease Framework Stakeholder Forum, and the British Society of Genetic Medicine. We plan to meet with the Wales Rare Disease Implementation Network and the UK Rare Disease Framework delivery partners. We are discussing the findings of the report and exploring a pragmatic approach to gaining more understanding of how rare conditions affect the UK population and how we can develop future solutions.

Factsheets to raise awareness of key facts and figures

We produced six clear and simple factsheets on key areas relating to rare conditions which are available on our new website, and we encouraged our members and stakeholders to share and use these factsheets in their own work. The six factsheets focus on: facts about rare, genetic and undiagnosed conditions; UK Rare Diseases Framework and Action Plans; diagnosis of rare conditions; coordinating care for rare conditions; newborn screening for rare conditions; and access to rare disease medicines in the UK.

Raising awareness through the media

We partnered with ITN Business to develop a high-quality online programme that can be widely shared by interested organisations and stakeholders. Our programme, 'Rare Conditions: The Stories Behind the Stats' went live on Rare Disease Day 2024 and uses a high-quality animation developed by the ITN graphics team to bring the facts and figures highlighted throughout this year's campaign to life. We also supported the Rare Diseases Campaign that launched within The Guardian and online through an exclusive piece from our Director of Policy, Nick Meade, exploring how to manage rare conditions in the UK effectively.

Raising awareness at Parliamentary receptions

We launched the Stats Behind the Stories report and raised awareness of key facts and figures about rare diseases at the Rare Disease Day Parliamentary receptions which took place during February and March 2024. We were joined by 188 attendees including speaker Andrew Stephenson MP Minister for Health and Secondary Care at the Westminster Rare Disease Day reception, 94 attendees including speaker Jenni Minto MSP Minister for Public Health and Women's Health at our Scottish Rare Disease Day reception, and over 80 attendees including speaker Professor Iolo Doull Medical Director at Welsh Health Specialised Services Committee at our Welsh Rare Disease Day reception. Each event included a passionate speaker from the rare disease community who discussed their personal experience of how living with a rare condition has affected them and their family.

We also hosted a virtual UK Rare Disease Day 2024 Four Nations reception with 113 people registered to attend. Speakers from England, Scotland, Wales and Northern Ireland shared learning

from the second year of the UK Rare Diseases Framework action plans and a deeper dive into their approaches to improving the lives of people affected by rare conditions.

Raising awareness among healthcare professionals and the public

Through regular workshops with our member charities and support groups and outreach at external virtual events, we grew a consortium of organisations working together to deliver a high impact communications campaign throughout February.

A wide range of charities and support groups downloaded our messages, graphics and materials to use on Rare Disease Day 2024 including: Behcets UK, CJD Support Network, CMTUK, Glut1 Deficiency UK, Lily Foundation, Metabolic Support UK, MyAware, Myotonic Dystrophy Support Group, Nerve Tumours UK, PIP-UK Poland Support Charity, PKD Charity, Ring20 Research Support, the Smith-Magenis Syndrome Foundation UK, TOFS UK, and Vasculitis UK.

We also worked closely with NHS England, the NHS Genomic Medicines Services, Genomics England and our member charity Medics for Rare Diseases so they could raise awareness of Rare Disease Day and key facts and figures about rare diseases with NHS staff and healthcare professionals through their own social media channels and newsletters.

Alongside EURORDIS we developed and launched a school toolkit to raise awareness of rare conditions among 8-12 year olds.

A strong legacy for future advocacy

In addition to underpinning awareness-raising on Rare Disease Day 2024, the central source of data about rare diseases in the UK published this year on our new website provides a strong legacy that we can build on in the coming years. Access to credible, authoritative and trusted data will help Genetic Alliance UK, our member organisations, and the wider rare disease community to advocate more effectively for people living with rare diseases in future.

Rare Resources guides

In 2022/23 we disseminated hard copies of Rare Resources Scotland and Rare Resources Cymru to key health and education professionals across Scotland and Wales. These are information guides for families who have recently received a diagnosis of a genetic or rare condition, are on the journey to receive a diagnosis or have been told their child's condition is so rare they may not get a diagnosis. The resources were developed and produced by Genetic Alliance UK in collaboration with families and support organisations, and provide links to reliable sources of information and support and 'top tips' from families. The resources promote signposting of people with rare, genetic and undiagnosed conditions to specialist charities and support groups.

During 2023/24 we made the Rare Resources Scotland and the bi-lingual Rare Resources Cymru available in an electronic format on our new website at geneticalliance.org.uk/support-and-information/rare-resources/ so they are easier for families to find and use.

In 2023/24 we also began work to develop a complementary set of Rare Resources England so that we can broaden our signposting and support for people living across the UK. The Rare Resource guides for England are being developed thanks to support from our industry partners, the Sir James Roll Trust, the Hospital Saturday Fund and The James Tudor Foundation.

3. Providing a strong voice for people living with genetic and rare conditions

A 'Manifesto for rare diseases' ahead of the coming General Election

During March 2024, a 'Manifesto for rare diseases' was shared with all of the main political parties thanks to partnership working between Genetic Alliance UK, the largest alliance of organisations supporting people with genetic, rare and undiagnosed conditions in the UK and the Specialised Healthcare Alliance, a coalition of patient groups and corporate supporters who campaign on behalf of people with rare and complex conditions.

Together, we called on the next government to commit to building on the current UK Rare Diseases Framework by setting new ambitions for improving the lives of people with rare conditions over the next five years. The manifesto sets out our calls to action, including policy changes that could:

- Help patients get a timely diagnosis
- Increase awareness among healthcare professionals
- Improve the coordination of care
- Increase access to specialised care, treatment and drugs.

The manifesto was shared with health ministers and shadow ministers from the Conservatives, Labour, the Liberal Democrats, Plaid Cymru and the Scottish National Party. Together, we asked all of the political parties to consider the UK's genetic, rare and undiagnosed condition population in developing proposals for their manifestos ahead of the coming General Election.

Raising awareness through the media of issues important to our members

During 2023-24 we've raised awareness of the challenges facing people with genetic and rare conditions through the national media. We've talked about [newborn heel prick testing](#) in The Sunday Times, about waiting times for genomic test results in The Times, and the [challenges facing families living with undiagnosed genetic conditions](#) on BBC Breakfast News. Most recently our Chief Executive, Louise Fish, took part in a round-table discussion about [how we can transform the lives of people living with rare diseases](#) hosted by the New Statesman.

Helping our members to engage with elected representatives across the UK

Genetic Alliance UK are the secretariat for the All Party Parliamentary Group and Cross Party Groups for rare, genetic and undiagnosed conditions in Westminster, the Senedd and Holyrood.

As the secretariat to the All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions in Westminster, we have worked to engage parliamentarians on key issues. In response to calls from the community and recent announcements in the rare condition space, the group has hosted events on care coordination, alert cards, cell and gene therapies and research into rare conditions. Over 20 of our member organisations have joined us in-person in Westminster to raise these challenges with parliamentarians, with many more joining these hybrid meetings online.

In Scotland, the Cross Party Group has been active in supporting work to develop a newborn screening pilot research programme for Spinal Muscular Atrophy and the broader issue of newborn screening for rare conditions. The group has looked at how decisions on newborn screening are made in Scotland and will continue to explore this issue in the coming year.

In Wales, the Cross Party Group co-hosted parliamentary drop-ins in the Senedd focused on genomics and raising awareness of newborn screening. The Welsh drop-in sessions enabled us to engage with a third of Senedd Members from across the political spectrum at each event.

Ensuring patient voices are heard by decision-makers

Our goal is to make sure that whenever decisions are made that impact on people living with genetic, rare and undiagnosed conditions, someone representing our community is present to make sure the decision is informed by the views of people with lived experience of these conditions. We prepare consultation responses on behalf of our community, attend meetings of committees and working groups, and disseminate representation opportunities to our members and people living with genetic, rare and undiagnosed conditions.

In 2023/24 we responded to a variety of consultations from the governments across the UK, healthcare and fertility regulators, healthcare delivery partners and other bodies, ensuring that the voices of our members and the rare community are involved in any decision making or policy development relevant to our community. Over the past year we responded to a total of 16 National Institute of Health and Care Excellence (NICE) scoping consultations, submitted patient perspective statements to the Human Fertilisation and Embryology Authority (HFEA) as evidence for 49 preimplantation genetic testing licence requests, and responded to a further 22 consultations by UK governments and the NHS on a variety of topics.

Shared learning roundtable for members on Managed Access Agreements

When NICE recommends a treatment with managed access, NHS England and the company responsible for the treatment develop a Managed Access Agreement (MAA). This is a short-term agreement setting out how people can access NHS-funded treatment so data can be collected to decide whether it should be available on the NHS in the longer term. In response to a member organisation asking for support to contribute to their first MAA, Genetic Alliance UK called together a group of its members with experience of MAAs for a shared learning roundtable to share their expertise with one another. The roundtable highlighted that many support groups faced similar challenges and experiences. We collated these themes into a Managed Access Agreements report and presented them to NICE and NHS England. This has prompted enhanced support from NICE for small charities contributing the views of people with rare conditions to MAAs.

4. Ensuring scientific breakthroughs in genomics drive better research and services

Making sure individuals and families benefit from genomic breakthroughs

Science is making great strides forward in genomics. However, people affected by genetic conditions and their families will only benefit if the UK also invests in clinical research programmes and NHS clinical genetics services. During 2023/24 we used high-profile speaking opportunities for our senior team at the Festival of Genomics and the NHS Genomics Healthcare Summit to raise awareness of the need to ensure individuals and families benefit from genomic breakthroughs. It is vital that findings from research projects and day-to-day clinical practice are shared with individuals and families in a timely way to help them make informed decisions about life-long treatment and care.

Supporting the development of pilot SWAN clinics

SWAN stands for syndromes without a name. It is not a diagnosis in itself, but a term used when a child or adult is believed to have a genetic condition and testing has failed to identify its genetic cause. People affected by a syndrome without a name can have a range of different symptoms and each person is likely to be affected differently. However, many children and adults affected by a syndrome without a name have global developmental delay, learning disabilities, physical disabilities or complex medical needs.

During 2023/24 we collaborated with the Welsh Government and Rare Disease Implementation Group to secure ongoing funding for the UK's first pilot Syndromes Without a Name clinic which is based in Cardiff. We coordinated input from the SWAN Cymru Council made up of parents of children affected by undiagnosed genetic conditions to develop Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) to measure benefits to patients referred to the clinic.

We also encouraged NHS England to set up two pilot SWAN clinics for adults and children in England. The development of a service specification for England began in 2023/24 with a view to NHS England commissioning two pilot SWAN clinics during 2024/25.

SWAN UK

Genetic Alliance UK is proud to run SWAN UK, the only dedicated support network in the UK for families affected by a syndrome without a name – a genetic condition so rare it often remains undiagnosed. The aim of SWAN UK is that every family gets the support that they need, regardless of whether or not they have a diagnosis.

During 2023/24 we welcomed 205 new individuals to our SWAN UK community making a total of almost 4,000 people. We organised 10 online coffee meetups to introduce families who are new to the SWAN UK community to other families with similar experiences. We organised 20 SWAN UK community events across England, Scotland and Wales, to bring members of the community together for activities including visits to theme parks, soft play, farms, theatres and picnic trips to the park.

In November 2023 we were delighted to announce that the National Lottery Community Fund will be helping us to deliver work in England over the next three years. We currently support over 2,470 families in England who have a child or children with an undiagnosed genetic condition, but we know there are far more families that need support. This funding will help us reach more families of undiagnosed children sooner, increase the diversity of our SWAN community, and create more opportunities for family events, advocacy and volunteering.

Undiagnosed Children's Day 2023

Undiagnosed Children's Day is our annual awareness day held on the last Friday in April. It's our chance to make as much noise as we can, increase awareness of undiagnosed genetic conditions and raise funds to ensure SWAN UK can carry on providing support to families who are affected by them. In 2023/24 Undiagnosed Children's Day took place on Friday 26 April.

Working in partnership with the Wales Gene Park

In Wales, Genetic Alliance UK works in partnership with the Wales Gene Park, an organisation embedded within the infrastructure for genomic research, education and wider public engagement. Working collaboratively, we raise awareness of the benefits of genomics through delivering events such as bi-monthly genomics cafes for the public and young people in Wales and beyond. We also support the involvement of a Patient and Public Sounding Board, made up of members of the rare disease and cancer genomics community to ensure coproduction is at the centre of the Welsh Genomics Delivery Plan.

Equity of access to cell and gene therapies

On behalf of ATMP Engage, a group where stakeholders collaborate on patient and public engagement, we carried out research to better understand the potential inequalities that could exist when delivering cell and gene therapies in the UK (also known as advanced therapeutic medicinal products or ATMPs). We produced a report on ATMPs and equity of access with recommendations to address these inequalities to ensure that everyone with a rare condition who may benefit from these types of therapies has equal access to them. We also facilitated involvement of people with lived experience in the cutting-edge pan-European ARDAT project, to directly influence the progress being made toward streamlining of cell and gene therapy development and regulation.

5. Promoting opportunities to expand screening in line with international best practice

Supporting research on new approaches to genomic screening

During 2023/24 we worked with Genomics England to inform the development of their new research programme focused on whole genome sequencing for newborn babies, the Generation Study.

The Generation Study is an NHS-embedded research study which will explore the benefits, challenges and practicalities of sequencing and analysing newborns' genomes. The study will sequence and analyse the genomes of 100,000 newborn babies in the UK. It is a hybrid clinic-research study that aims to generate evidence on whether whole genome sequencing can be used to screen newborns for more than 200 rare genetic conditions, and to assess the feasibility of doing this within the NHS.

In 2023/24 we co-chaired Genomics England's new Generation Study working group on communicating results and onward support which gave us an opportunity to ensure those crucial first moments on a rare condition journey are delivered appropriately, with a balanced and informative approach to introducing new parents to the risk that their child may develop a rare condition. We were able to bring the expertise of our member organisations who already receive 'screen positive' messages through the newborn bloodspot 'heelprick' programme to this development process. We also sit on the Ethics Working Group for this significant research study.

In September 2023 an initial list of over 200 genetic conditions that will be screened for by the Generation Study was published. Genomics England joined us for a special Member Briefing and hosted virtual drop-in sessions to talk to our members about how this research study could affect charities supporting people living with rare genetic conditions and the people they support.

Our research staff are part of the independent evaluation team (led by researchers at UCL and Great Ormond Street Hospital for Children NHS Foundation Trust) that was awarded the contract to assess the process and impact of the Generation Study, after competitive tender. This work will begin in 2024/25.

Working collaboratively to raise awareness of the potential to expand current newborn screening programmes in the UK

Some of the appetite for genomic screening from families living with genetic and rare conditions is because the UK is not extracting all of the potential from its conventional newborn and population screening programmes. For example, the newborn bloodspot 'heelprick' test given to every newborn baby in the UK currently screens for a maximum of nine conditions, but there are more than 20 European countries screening for more than the UK, with most of those screening for 20 conditions or more.

We continue to be part of the Newborn Screening Collaborative chaired by the MPS Society. We are also members of the Blood Spot Task Group of the UK National Screening Committee which works towards fulfilling the UK Rare Disease Framework objective of improving the evidence base to help the committee make rapid and robust decisions about newborn screening for rare diseases.

Raising awareness of international best practice

Our approach to the current newborn screening programme is informed by our understanding of international best practice in this area. We work collaboratively with Eurordis – Rare Diseases Europe and their working group on newborn screening.

We also work with Screen4Care, a European project examining newborn screening using genome sequencing, as well as looking at AI tools to examine health records to identify rare conditions. We are members of their Patient Advisory Board and of their multi-stakeholder forum.

This year and the coming year

Delivering the 2023/24 Business Plan

Our 2023/24 business plan focused on 'doing what we already do better' to tackle internal challenges facing the charity and put us in a strong position to implement our new five-year strategy once approved. Our focus was on:

- Clarifying our offer to member organisations and delivering it to a high standard.
- Launching a new website to improve understanding of what we do and why it matters.
- Building on our strengths of the policy and research teams and their clear focus on
 - implementing the UK Rare Diseases Framework
 - providing a strong voice for the genetic and rare community
 - driving better research and services for people living with genetic conditions
 - and promoting opportunities to expand screening in the UK.
- Clarifying and improving our offer to the SWAN UK community.
- Improving our approach to fundraising, income generation and corporate services.

We took urgent steps to address the financial challenges facing Genetic Alliance UK through a change management programme focused on cost savings, income generation and reducing headcount. We made cost savings by decreasing our office and storage space. We diversified our income by implementing a fundraising strategy including new approaches to individual giving, community fundraising, corporate partnerships, and in-memory and legacy gifts. We sadly made three posts at the charity redundant. This work was supported by the second year of a sustainability grant from the Wellcome Trust which helped us to develop our new five-year strategy, build our fundraising capabilities, and modernise our approach to equality, diversity and inclusion.

During 2023/24 we also implemented the recommendations made in our governance review by:

- Recruiting four new trustees to increase the independence and diversity of the Board.
- Introducing a new People and Policies sub-committee, alongside the existing Finance and Governance sub-committee, to share the workload and involve more trustees. The new sub-committee will provide oversight for recruitment of trustees and senior staff, HR, pay and reward, and policies in areas such as data protection, health and safety, and safeguarding.
- Amending the Articles of Association in line with best practice for trustee length of service, membership eligibility criteria, and codes of conduct for trustees and members.

Looking forward to 2024/25

2024/25 is the first year of our new five-year strategy working together to improve the lives of people affected by genetic and rare conditions.

During 2024/25 our business plan will focus on:

- Continuing to address the significant financial challenges facing the charity by prioritising income generation, making the charity sustainable and rebuilding our reserves.
- Providing a strong, unified voice for our community before and after the UK General Election.
- Continuing our strategic focus on delivering the UK Rare Diseases Framework.
- Providing patient and public voice expertise to ensure new research programmes are shaped by the views of people with lived experience, and promoting a culture in academic and health services of valuing and acting on this input.
- Scoping a new strategic programme of work on screening and securing the funds to deliver it.
- Investing in and making the most of the skills and capacity of our committed staff.

We will continue to take urgent steps to manage the financial challenges facing the charity by:

- Recruiting a new Chief Executive who will complement the skills of our senior team with expertise in business development and income generation, governance, strategic delivery, impact measurement, operational management, business planning and financial management.
- Diversifying income by developing new strategic funding partnerships with research funders and LifeArc and securing a core funding grant from the Department of Health and Social Care.
- Making cost savings by closing our remaining office and storage space and consulting with staff on a major restructure in Q1 2024/25 with a view to ensuring the charity is financially sustainable and can rebuild its reserves.

This work will be supported by the final year of a sustainability grant from the Wellcome Trust to continue building our fundraising capabilities, and modernising our approach to equality, diversity and inclusion.

We have moved three strategic priorities into 2025/26 (the second year of our five-year strategy) so trustees and senior staff can focus on making the charity sustainable. These are:

- Scoping a new strategic programme of work on genomics and building relationships with potential partners and funders for this work.
- Finding partners and funders for a major project to map and signpost people with rare conditions to: charities and support groups for their condition; NHS expertise or centres of excellence for their condition; information about any existing treatment options for their condition; and opportunities to take part in clinical trials of new treatments for their condition.
- Finding a long-term home for the SWAN UK community and supporting change management to ensure that the community are well-supported through this process.

Thank you to our supporters and funders

We raise funds for our vital work with and on behalf of members through individual giving, community fundraising, trusts and foundations, corporate supporters and legacies and in memory giving.

Thank you to all of the individuals and organisations who have supported our work this year. We are so grateful to everyone who has worked with us, volunteered or fundraised for us, or supported our work in other ways.

We wish to extend our thanks and gratitude to the families and friends who chose to remember their loved ones through a legacy or in memory donation to support our work during 2023/24.

We would also like to thank all of our funders who have given grants, sponsorship or donations to support our work this year. These organisations are listed here.

Alexion
Amicus
Anthony Walton Trust
BioCryst
Catherine Cookson Charitable Trust
Chiesi
The Clothworkers Foundation
Egetis
The Hospital Saturday Fund
Ipsen
The James Tudor Foundation
Janssen
Kyowa Kirin
LifeArc
National Lottery Community Fund
Novartis
Orchard Therapeutics
Pfizer
PTC
Robert Luff Foundation
Roche
Sir James Roll Trust
St Andrews Charity Fashion Show
Takeda
UCB
Ultragenyx
Vertex
Wellcome Trust

Treasurer's letter and financial review

Thank you to all our members, supporters and funders. You have ensured the work outlined in this report could continue during a time that continues to be very challenging for the charity and the people we support.

Review of the financial position

Income

The results for the year are set out in the statement of financial activities on page 31. The total income for the year was £780,935 (£741,859 in 2023).

This represents an overall increase of 5%, however, this was not experienced evenly across all sources of income. General fundraising remains challenging, which has emphasised the importance of our trust and foundation, corporate and government funders. I would particularly like to note the contribution from the Wellcome Trust, which has helped to ensure our organisational resilience.

Expenditure

Total expenditure for the year was £862,752 (£769,204 in 2023).

This represents a 12% increase on the prior year and reflects a continued focus on cost control. The mix of expenditure remained consistent over the period with policy work at 36%, membership and engagement at 37%, research at 14% and raising funds at 13%, which means 87% of our spending is on charitable activities.

Surplus/deficit

Our final financial position for the year across all funds is a deficit of £81,817 (deficit of £27,345 in 2023).

This is comprised of a deficit of £63,262 on unrestricted funds and a deficit of £18,555 on restricted funds.

Reserves policy

Total reserves at the end of the financial year are £41,846 (£123,663 in 2023).

This is made up of restricted reserves of £12,134 (£30,689 in 2023) and unrestricted reserves of £29,712 (£92,974 in 2023).

The change in reserves is due to the in-year deficits noted above.

Our unrestricted reserves represent less than two months of unrestricted expenditure at the year end. This is considerably below the Trustees' target in the medium term to hold unrestricted reserves that equate to approximately six months of unrestricted expenditure.

The Board and Executive are clear that income generation and cost control measures need to continue to ensure that we can maintain and maximise our impact in the years ahead.

Conclusion

Like many organisations, Genetic Alliance UK continued to face a challenging environment in 2023/24 with financial volatility and the cost of living crisis depressing charitable donations and placing inflationary pressure on costs. However, any adverse effects were countered by careful planning and budgeting as well as a change management programme.

These circumstances resulted in an unrestricted fund deficit for the year of c £57k compared to a deficit for the previous year of c £33k. Unrestricted free reserves (general and designated funds) stand at approximately £24k as at 31 March 2024. In response, the Trustees have implemented a change management programme focused on income generation, cost savings and reductions in headcount. This resulted in us making a number of posts redundant in 2023/24 and we are consulting with affected staff on a further restructure in Q1 2024/25 with a view to ensuring the charity is financially sustainable and can rebuild its reserves.

The Trustees are mindful that they are likely to continue to operate in an environment of economic uncertainty and challenge and have reviewed budgets and forecasts for the next 12 months on that basis. This work, informed by prudent assumptions and focused on ensuring financial sustainability and rebuilding reserves, indicates that the Charity will make a surplus in the year ending 31 March 2025 and that adequate liquid resources will continue to be available to fund activities.

Accordingly, the Trustees consider it appropriate for the Charity to continue to adopt the going concern basis in preparing its financial statements.



David Ramsden
Treasurer, Board of Trustees

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.

In 2023/24 we updated our Articles of Association in line with best practice for trustee length of service, membership eligibility criteria and codes of conduct for trustees and members.

Appointment and training of Trustees

Nine trustees are elected by the membership, and three trustees are appointed by the Board in order to increase diversity. Members co-opted in year and new nominees must be proposed and seconded by a member. Trustee appointments are for three years, after which trustees retire but are eligible for re-election for a further term of three years. New trustees must undertake an induction and are provided with an information pack detailing the charity's work, governance, management policies and procedures, and potential conflicts of interest that may arise.

In 2023/24 we recruited four new trustees to increase the independence and diversity of the Board. At the Annual General Meeting in September 2023 our members voted to adopt the revised Articles of Association, elect one new member trustee, and note the appointment by the Board of three new independent trustees.

Governance and organisational management

Trustees held four Board meetings in the year ending 31 March 2024, where they reviewed the charity's performance and determined and approved operating plans and budget.

During 2023/24 Trustees also held a Board Away Day to discuss implementation of our new five-year strategy which was launched at the charity's Annual General Meeting in Autumn 2024.

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 met six times during 2023/24. The F&G committee provides detailed oversight and advice to the Board of Trustees in relation to financial management, financial viability, risk management and governance. The F&G committee has a minimum of three Trustee members, appointed from and by the Board of Trustees that includes the Treasurer (Chair of the Committee), Chair of Genetic Alliance UK, and the Deputy Chair. The Chief Executive and Directors of Genetic Alliance UK are ex officio.

In 2023/24 we introduced a new People and Policies (P&P) committee chaired by a nominated Trustee. The P&P committee will meet at least two times a year to oversee recruitment of trustees and senior staff, human resources policies, pay and reward, and policies on data protection, health and safety, safeguarding, and risk and compliance.

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 at each meeting of the Board of Trustees and by the F&G committee. The main risks the charity has identified are the low level of unrestricted funds, due to volatile charitable giving, and the cash flow issues this may cause. The charity has taken measures to reduce its cost base, and to find new sustainable forms of funding. In particular, the charity has built an ongoing relationship with funders who can support

unrestricted expenditure and research partnerships which fund our research team. These measures have meant that these identified risks are being mitigated against.

Fundraising

Genetic Alliance UK undertakes most of its fundraising activities in-house, but used a consultant during 2023/24 solely for the purpose of large grant applications. Genetic Alliance UK is registered with the Fundraising Regulator and adheres to the codes of ethics laid out by the Fundraising Regulator and The Code of Fundraising practice in relation to all fundraising activities. The charity received no complaints about its fundraising practice in this financial year.

Working with the life-sciences industry

Genetic Alliance UK receives support from industry partners for projects that help us to deliver our charitable objectives. Our [policy on working with industry](#) sets out clear principles and guidance for how we work with the life-sciences industry.

Reference and administrative detail

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined in the Companies Act 2026.

Registered company number

05772999

Registered charity numbers

1114195 and SC039299

Registered office

The Clock Tower, 5 Farleigh Court, Old Weston Road, Flax Bourton, Bristol BS48 1UK

Postal address

3rd Floor, 86-90 Paul Street, London EC2A 4NE

Trustees

Ms Lara Bloom (joined September 2023)

Ms Gloria Clark (Chair of People and Policy Committee)

Ms Phillippa Farrant

Mr Toby Hannam (joined September 2023)

Miss Sara Hunt

Mr Neil McClements

Mrs Sue Millman (Vice Chair)

Dr Shehla Mohammed (joined September 2023)

Mrs Elizabeth Porterfield MBE (Chair)

Mr David Ramsden (Treasurer and Chair of Finance and Governance Committee)

Mr Greg Stevenson (joined September 2023)

Dr Sarah Wynn

Board observer

Robin Nott

Chief Executive Officer

Louise Fish

Senior Management Team

Dr Amy Hunter, Nick Meade, Mary Edwards

Auditors

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

Management accountant

Fiona Bevan of Bevan Financial Management Ltd

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

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

Website	geneticalliance.org.uk
Facebook	GeneticAllianceUK
Twitter	GeneticAll_UK
Instagram	GeneticAllianceUK
LinkedIn	Genetic Alliance UK

Trustee responsibility

The Trustees (who are also directors of Genetic Alliance UK Ltd for the purpose of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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

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

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Charity SORP.
- Make judgments and estimates that are reasonable and prudent.
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

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 to enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the Trustees are aware:

- There is no relevant audit information of which the charitable company's auditors are unaware.
- 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 auditors are aware of that information.

Auditors

The auditors, Nyman Libson Paul Chartered Accountants, will be proposed for re-appointment at the forthcoming Annual General Meeting.

Report of the Trustees, incorporating a strategic report, approved by order of the Board of Trustees, as the company directors on 29 July 2024 and signed on the Board's behalf by:



Elizabeth Porterfield
Chair, Board of Trustees

Independent Auditor's report to the members of Genetic Alliance UK

Independent Auditor's Report to the Members of Genetic Alliance UK

Opinion

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2024 set out on pages 31 to 48 which comprise the statement of financial activities, the balance sheet, the cash flow statement and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

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 2024, 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 regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the trustees' annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the directors' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Board of Trustees and Accounts.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require 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 directors' 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.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement set out on page 26 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, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

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

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We gained an understanding of the legal and regulatory framework applicable to the Charity and the industry in which it operates, and considered the risk of acts by the company that were contrary to applicable laws and regulations, including fraud. We designed audit procedures to respond to the risk, recognising that the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

We focussed on laws and regulations which could give rise to a material misstatement in the financial statements, including, but not limited to, the Charities Act 2011 and Companies Act 2006. Our tests included agreeing the financial statement disclosures to underlying supporting documentation and enquiries with management. There are inherent limitations in the audit procedures described above and, the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. We did not identify any key audit matters relating to irregularities, including fraud. As in all our audits, we also addressed the risk of management override of internal controls, including testing journals and evaluating whether there was evidence of bias by the trustees that represented a risk of material misstatement due to fraud.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities . This description forms part of our Auditors' Report.

Use of our report

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 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 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 charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Andrew Thomas (Senior statutory auditor)
for and on behalf of

Nyman Libson Paul LLP
Chartered Accountants
Registered Auditors
124 Finchley Road
London
NW3 5JS

Date: 30 July 2024

GENETIC ALLIANCE UK LTD

STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME AND EXPENDITURE ACCOUNT)

YEAR ENDED 31 MARCH 2024

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £	Total Funds 2023 £
Income from:					
Donations and legacies	2	452,198	222,645	674,843	690,024
Charitable activities	3	55,885	50,068	105,953	51,730
Investments		139	-	139	105
Total income		<u>508,222</u>	<u>272,713</u>	<u>780,935</u>	<u>741,859</u>
Expenditure on:					
Raising funds	4	111,653	-	111,653	94,391
Charitable activities	5	453,758	297,341	751,099	674,813
Total expenditure		<u>565,411</u>	<u>297,341</u>	<u>862,752</u>	<u>769,204</u>
Net income/(expenditure)	8	(57,189)	(24,628)	(81,817)	(27,345)
Transfers between funds	18	(6,073)	6,073	-	-
Net movement in funds		(63,262)	(18,555)	(81,817)	(27,345)
Total funds at start of year	18	92,974	30,689	123,663	151,008
Total funds at end of year	18	<u>29,712</u>	<u>12,134</u>	<u>41,846</u>	<u>123,663</u>

The Charity has no recognised gains or losses other than the results for the year as set out above.

All of the activities of the charity are classed as continuing.

The notes on pages 34 to 48 form part of these financial statements
See note 11 for fund-accounting comparative figures

GENETIC ALLIANCE UK LTD

BALANCE SHEET

AS AT 31 MARCH 2024

Company number: 05772999

	Note	2024 £	2023 £
Fixed assets			
Tangible assets	12	5,634	4,698
		<u>5,634</u>	<u>4,698</u>
Current assets			
Debtors	13	101,901	53,368
Cash at bank and in hand		85,583	141,457
		<u>187,484</u>	<u>194,825</u>
Liabilities			
Creditors : amounts falling due within one year	14	(151,272)	(75,860)
		<u>36,212</u>	<u>118,965</u>
Net current assets			
		<u>36,212</u>	<u>118,965</u>
Total assets less current liabilities			
		<u>36,212</u>	<u>118,965</u>
Net assets			
		<u>41,846</u>	<u>123,663</u>
FUNDS			
Unrestricted funds			
General funds	19	29,712	46,040
Designated funds	19	-	46,934
Restricted funds	19	12,134	30,689
		<u>41,846</u>	<u>123,663</u>
Total funds			
		<u>41,846</u>	<u>123,663</u>

These financial statements have been prepared in accordance with the special provisions for small companies under Part 15 of the Companies Act 2006.

These financial statements were approved by the Trustees on and are signed on their behalf by:

Elizabeth Porterfield, MBE
Chair of Trustees

The notes on pages 34 to 48 form part of these financial statements

GENETIC ALLIANCE UK LTD

CASH FLOW STATEMENT

YEAR ENDED 31 MARCH 2024

	Note	2024 £	2023 £
Net cash inflow from operating activities	15	(52,493)	(53,457)
Non-operational cash flows:			
Investing activities			
Payments for tangible fixed assets		(3,381)	(4,368)
		<u>(3,381)</u>	<u>(4,368)</u>
Net cash inflow/(outflow) for the year	16	<u><u>(55,874)</u></u>	<u><u>(57,825)</u></u>

Cashflow Restrictions

Charity law prohibits the use of net cash inflows on any endowed or other restricted fund to offset net cash outflows on any fund outside its own objects, except on special authority. In practice, this restriction has not had any effect on cash flows for the year.

The notes on pages 34 to 48 form part of these financial statements

GENETIC ALLIANCE UK LTD

NOTES TO THE FINANCIAL STATEMENTS

YEAR ENDED 31 MARCH 2024

1 Accounting policies

Accounting convention

The financial statements have been prepared in accordance with the historical cost convention (except for investments which have been included at fair value) and in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) issued in October 2019 and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005, the Charities Accounts (Scotland) Regulations 2006 and UK Generally Accepted Practice as it applies from 1 January 2019.

The charity is a public benefit entity as defined under FRS102.

Going concern

Like many organisations, Genetic Alliance UK continued to face a challenging environment in 2023/24 with financial volatility and the cost of living crisis depressing charitable donations and placing inflationary pressure on costs. However, any adverse effects were countered by careful planning and budgeting as well as a change management programme.

These circumstances resulted in an unrestricted fund deficit for the year of c £57k compared to a deficit for the previous year of c £33k. Unrestricted free reserves (general and designated funds) stand at approximately £24k as at 31 March 2024. In response, the Trustees have implemented a change management programme focused on income generation, cost savings and reductions in headcount. This resulted in us making a number of posts redundant in 2023/24 and we are consulting with affected staff on a further restructure in Q1 2024/25 with a view to ensuring the charity is financially sustainable and can rebuild its reserves.

The Trustees are mindful that they are likely to continue to operate in an environment of economic uncertainty and challenge and have reviewed budgets and forecasts for the next 12 months on that basis. This work, informed by prudent assumptions and focused on ensuring financial sustainability and rebuilding reserves, indicates that the Charity will make a surplus in the year ending 31 March 2025 and that adequate liquid resources will continue to be available to fund activities.

Accordingly, the Trustees consider it appropriate for the Charity to continue to adopt the going concern basis in preparing its financial statements.

Income

Income from donations is included in income when these are receivable, except as follows:

- I. When donors specify that donations given to the charity must be used in future accounting periods, the income is deferred until those periods;
- II. When donors impose conditions which have to be fulfilled before the charity becomes entitled to use such income, the income is deferred until the pre-conditions have been met.

Grants, including government grants are accounted for as receivable and are allocated to Income from Donations and Legacies. Other grants which are received subject to the charity providing a specific level of service are included within Income from Charitable Activities.

Membership income is accounted for as receivable.

Investment income is included on a receivable basis.

Donations in kind comprise donated services where the costs are measurable and the services would otherwise have to be paid for to maintain operational effectiveness.

GENETIC ALLIANCE UK LTD
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 31 MARCH 2024

1 Accounting policies (*continued*)

Expenditure

Expenditure is recognised in the period in which it is incurred. Expenditure includes attributable VAT which cannot be recovered.

Raising funds

Raising funds expenditure include those costs incurred in seeking voluntary contributions and other costs which include the costs of running and participating in fundraising events and collections.

Charitable Activities

Grants awarded are allocated to charitable activities.

Grants awarded are treated as expenditure and a liability in the accounts as soon as they become legal or constructive obligations. In the case of multi-year grant awards, the funding for all years is immediately recognised unless there are conditions which need to be met by the recipient to enable the release of subsequent years' funding.

Governance costs

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity. Governance costs are included within support costs.

Allocation and apportionment costs

Certain expenditure is directly attributable to specific activities and this has been included in those cost categories. Other costs, which are attributable to more than one category, are apportioned across cost categories on the basis of an assessment of workload carried out from time to time.

Overhead support costs have been allocated between fundraising and charitable activities. The apportionment has been allocated on the basis of usage and is analysed in note 6.

Redundancy costs

The charity recognises redundancy costs at the point at which the redundancy has been confirmed and communicated to the individual. The costs are allocated to the same activity as the member of staff was engaged in.

Pension costs and other post-retirement benefits

The charity contributes to defined contribution pension schemes. Contributions payable to the charity's pension schemes are charged to the Statement of Financial Activities in the period to which they relate.

Fixed assets

Fixed assets are held at cost less accumulated depreciation. Assets costing less than £500 are not capitalised.

Depreciation is charged on assets at the following rates:

Office equipment - 3 years straight line

Debtors

Debtors are initially measured at the settlement amount after any trade discounts. Subsequently they are measured at the value of the consideration expected to be received.

GENETIC ALLIANCE UK LTD
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 31 MARCH 2024

1 Accounting policies (*continued*)

Cash

Cash balances represent cash and cash equivalents held with a maturity date of less than one year and are included at fair value.

Creditors

Creditors are measured at the settlement amount less any trade discounts.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objects at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Designated funds form part of unrestricted funds and have been identified as being for particular purposes by the Trustees. They are not restricted and can be transferred to general funds at any time at the discretion of the Trustees.

Further explanation of the nature and purpose of each fund is included in note 18 to the financial statements.

2 Income from donations and legacies

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Donations from supporters	399,279	58,778	458,057
Legacies received	208	-	208
Robert Luff Trust	-	20,000	20,000
Wellcome Trust	-	50,000	50,000
Great Ormond Street Hospital	-	10,324	10,324
<i>Grants from Government</i>			
National Lottery funding	-	67,693	67,693
Scottish Government	-	9,950	9,950
Other grants received	3,000	5,900	8,900
<i>Donations through fundraising:</i>			
Online donations	49,711	-	49,711
	<u>452,198</u>	<u>222,645</u>	<u>674,843</u>

GENETIC ALLIANCE UK LTD
NOTES TO THE FINANCIAL STATEMENTS
YEAR ENDED 31 MARCH 2024

2 Income from donations and legacies (*continued*)

Prior year

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Donations from supporters	379,197	22,008	401,205
Legacies received	8,325	-	8,325
Robert Luff Trust	-	20,000	20,000
Wellcome Trust	-	80,000	80,000
University College London	-	6,805	6,805
Genome Research Ltd	9,150	-	9,150
PF Charitable Trust	-	2,000	2,000
Great Ormond Street Hospital	-	20,320	20,320
ICS	8,000	-	8,000
<i>Grants from Government</i>			
National Lottery funding	-	69,817	69,817
Scottish Government	-	10,000	10,000
Other grants received	3,930	2,000	5,930
<i>Donations through fundraising:</i>			
Online donations	48,472	-	48,472
	<u>457,074</u>	<u>232,950</u>	<u>690,024</u>

3 Income from: Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Consultancy work	55,885	50,068	105,953
	<u>55,885</u>	<u>50,068</u>	<u>105,953</u>

Prior year

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Consultancy work	43,717	8,013	51,730
	<u>43,717</u>	<u>8,013</u>	<u>51,730</u>

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4 Expenditure on: Raising funds

	Total Funds 2024 £	Total Funds 2023 £
Staff costs, including consultancy work	106,009	85,432
Fees	2,083	1,493
Other direct costs	6	181
Support costs (Note 6)	3,555	7,285
	<u>111,653</u>	<u>94,391</u>

5 Expenditure on Charitable activities

	Direct Costs £	Support Costs (Note 6) £	Total Funds 2024 £
Membership and Engagement	184,486	136,136	320,622
Policy work	151,707	160,271	311,978
Research	61,856	56,643	118,499
	<u>398,049</u>	<u>353,050</u>	<u>751,099</u>

Prior year

	Direct Costs £	Support Costs (Note 6) £	Total Funds 2023 £
Membership and Engagement	185,866	99,762	285,628
Policy work	145,070	179,657	324,727
Research	27,291	37,167	64,458
	<u>358,227</u>	<u>316,586</u>	<u>674,813</u>

£294,885 of the above support costs in notes 4 and 5 and £270,039 of direct costs relate to unrestricted funds spent during the year. £61,230 of support costs and £236,111 of direct costs relates to restricted funds spent during the year.

£211,781 of the above support costs in notes 4 and 5 and £322,971 of direct costs relate to unrestricted funds spent during the prior year. £112,089 of support costs and £122,363 of direct costs relates to restricted funds spent during the prior year.

GENETIC ALLIANCE UK LTD
NOTES TO THE FINANCIAL STATEMENTS
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6 Support costs

Support costs are allocated between raising funds and charitable activities on the basis of usage. Support costs, included in notes 4 & 5, are as follows:

	Raising Funds £	Charitable Activities £	Total 2024 £
Staff costs	-	206,350	206,350
Communications	-	2,187	2,187
Office and admin costs	3,555	70,162	73,717
Travel	-	10,634	10,634
Finance costs	-	1,568	1,568
Professional fees	-	48,109	48,109
Governance costs (Note 7)	-	14,040	14,040
	<u>3,555</u>	<u>353,050</u>	<u>356,605</u>

Prior year

	Raising Funds £	Charitable Activities £	Total 2023 £
Staff costs	-	181,122	181,122
Communications	-	4,828	4,828
Office and admin costs	7,285	63,342	70,627
Travel	-	7,513	7,513
Finance costs	-	749	749
Professional fees	-	46,972	46,972
Governance costs (Note 7)	-	12,060	12,060
	<u>7,285</u>	<u>316,586</u>	<u>323,871</u>

7 Governance costs

	Total Funds 2024 £	Total Funds 2023 £
Auditor's fees - for audit services	10,800	9,000
Accounts review	3,240	3,060
	<u>14,040</u>	<u>12,060</u>

GENETIC ALLIANCE UK LTD
NOTES TO THE FINANCIAL STATEMENTS
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8 Net income/(expenditure) for the year

This is stated after charging:

	2024	2023
	£	£
Auditor's remuneration - for audit services	10,800	9,000
Trustees' travel expenses (4 trustees, 2023: 3 trustees)	2,419	2,325
Depreciation	2,445	662
	<u>15,664</u>	<u>11,987</u>

No Trustee received any remuneration during the year.

9 Staff costs and numbers

The aggregate payroll costs were:

	2024	2023
	£	£
Wages & salaries	577,413	499,662
Social security costs	57,823	51,212
Pension contributions	33,371	28,421
Redundancy costs (2 employees)	3,635	-
	<u>672,242</u>	<u>579,295</u>

The number of employees whose employee benefits exceeded £60,000 during the year were:

	2024	2023
Between £60,000 and £70,000	1	-
Between £70,001 and £80,000	<u>-</u>	<u>1</u>

The average weekly number of employees during the year was 17 (2023: 16), calculated on the basis of average headcount. The total employment benefits received by key management personnel including employer's national insurance and employer's pension contributions were £236,405 (2023: £173,181). There were no outstanding redundancy costs due at the end of the year.

10 Taxation

The charity is exempt from corporation tax on its charitable activities.

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11 Statement of Financial Activities comparative figures

For the year ended 31 March 2023	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Income from:			
Donations and legacies	457,074	232,950	690,024
Charitable activities	43,717	8,013	51,730
Investments	105	-	105
Total income	<u>500,896</u>	<u>240,963</u>	<u>741,859</u>
Expenditure on:			
Raising funds	94,391	-	94,391
Charitable activities	440,361	234,452	674,813
Total expenditure	<u>534,752</u>	<u>234,452</u>	<u>769,204</u>
Net income/(expenditure)	(33,856)	6,511	(27,345)
Transfers between funds	(7,827)	7,827	-
Net movement in funds	(41,683)	14,338	(27,345)
Total funds at start of year	134,657	16,351	151,008
Total funds at end of year	<u>92,974</u>	<u>30,689</u>	<u>123,663</u>

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12 Tangible fixed assets

	Office equipment £	Total £
Cost or valuation		
At 1 April 2023	5,646	5,646
Additions	3,381	3,381
At 31 March 2024	<u>9,027</u>	<u>9,027</u>
Depreciation		
At 1 April 2023	948	948
Charge for the year	2,445	2,445
At 31 March 2024	<u>3,393</u>	<u>3,393</u>
Net book value		
At 31 March 2024	<u>5,634</u>	<u>5,634</u>
At 31 March 2023	<u>4,698</u>	<u>4,698</u>

13 Debtors

	2024 £	2023 £
Due in less than one year:		
Trade debtors	97,724	46,325
Prepayments and accrued income	3,517	6,383
Other debtors	660	660
	<u>101,901</u>	<u>53,368</u>

14 Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	4,700	4,333
Social security and other taxes	38,685	14,298
Other creditors	4,780	7,465
Accruals and deferred income	103,107	49,764
	<u>151,272</u>	<u>75,860</u>

GENETIC ALLIANCE UK LTD
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15 Reconciliation of net movement in funds to net cash inflow from operating activities

	2024 £	2023 £
Statement of Financial Activities: Net movement in funds	(81,817)	(27,345)
Depreciation	2,445	662
(Decrease)/increase in creditors: current liabilities	75,412	(39,555)
Decrease / (increase) in debtors	(48,533)	12,781
Net cash inflow/(outflow) from operating activities	<u><u>(52,493)</u></u>	<u><u>(53,457)</u></u>

16 Analysis of changes in cash during the year

	2024 £	2023 £	Change £
Cash at bank and in hand	<u>85,583</u>	<u>141,457</u>	<u>(55,874)</u>
	2023 £	2022 £	Change £
Cash at bank and in hand	<u>141,457</u>	<u>199,282</u>	<u>(57,825)</u>

GENETIC ALLIANCE UK LTD
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17 Analysis of changes in net debt

	1 April 2023 £	Cashflow Movements £	31 March 2024 £
Cash at bank and in hand	141,457	(55,874)	85,583
	<u>141,457</u>	<u>(55,874)</u>	<u>85,583</u>
Prior year	1 April 2022 £	Cashflow Movements £	31 March 2023 £
Cash at bank and in hand	199,282	(57,825)	141,457
	<u>199,282</u>	<u>(57,825)</u>	<u>141,457</u>

GENETIC ALLIANCE UK LTD
NOTES TO THE FINANCIAL STATEMENTS
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18 Movement in Funds

For the year ended 31 March 2024

	At 1 April 2023 £	Income £	Expenditure £	Transfers £	At 31 March 2024 £
Restricted funds					
ARDAT	-	6,772	(6,772)	-	-
Community Ask 2023	-	85,850	(85,850)	-	-
Genomics England accessible information	-	2,613	(2,613)	-	-
Generation evaluation	-	4,152	(4,243)	-	(91)
Captivate	-	-	(1,684)	-	(1,684)
RD Research hub	-	13,717	(13,717)	-	-
SWAN UK Wales	22,012	14,313	(39,074)	2,749	-
SWAN UK National lottery	-	53,380	(39,471)	-	13,909
Wellcome 2023/25	-	50,000	(50,000)	-	-
Robert Luff Rare Experience	-	4,311	(4,311)	-	-
Robert Luff SWAN Couples	-	7,908	(7,908)	-	-
Robert Luff Trust	-	7,781	(7,781)	-	-
NHS Scotland	-	8,773	(8,803)	30	-
Alex TLC X-ALD study	-	2,819	(2,819)	-	-
Rapid Genome Sequencing	8,677	10,324	(19,001)	-	-
ATMP	-	-	(3,294)	3,294	-
	<u>30,689</u>	<u>272,713</u>	<u>(297,341)</u>	<u>6,073</u>	<u>12,134</u>
Unrestricted funds					
General funds	46,040	169,099	(179,319)	(6,108)	29,712
Designated funds					
Rare Disease Day	-	100,135	(100,170)	35	-
Rare Disease UK General Donations	15,441	209,747	(225,188)	-	-
SWAN UK: General Donations	31,493	29,241	(60,734)	-	-
	<u>92,974</u>	<u>508,222</u>	<u>(565,411)</u>	<u>(6,073)</u>	<u>29,712</u>
Total funds	<u>123,663</u>	<u>780,935</u>	<u>(862,752)</u>	<u>-</u>	<u>41,846</u>

Fund descriptions

Restricted funds

ARDAT - funds received to support a project on Accelerating Research and Development for Advanced Therapies.

Community Ask 2023 - funds received to develop and launch a new unified website for Genetic Alliance UK, Rare Disease UK and SWAN UK.

Genomics England accessible information - funds received to develop a toolkit helping charities and support groups to develop accessible information about genetic conditions.

Generation Evaluation - funds received to support evaluation of parent experiences in the pilot 'Generation Study' run by Genomics England.

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18 Movement in funds (continued)

CAPTIVATE - funds received to support a Rare Disease Research UK Hub node on Changing Clinical Practice Through Innovative Trial Design (CAPTIVATE).

RD Research Hub - funds received to deliver the Rare Disease Research UK Hub in partnership with Newcastle University and The Newcastle upon Tyne Hospitals NHS Foundation Trust.

SWAN UK Wales - funds received for the development of a support network in Wales for families with children affected by undiagnosed genetic conditions.

SWAN UK England National Lottery fund- funds received to strengthen our support for families affected by undiagnosed genetic conditions in England.

Wellcome 23-25 - funding received from the Wellcome Trust for strategy development, implementation of a quality and diversity review and fundraising support.

Robert Luff trust - funds received from the trust for undertaking research.

Robert Luff Rare experience/SWAN Couples - funds received from the trust for undertaking research relating to SWAN Couples counselling.

NHS Scotland - funds received to advance work related to priority two of the UK Rare Disease Framework (Raising awareness with health professionals) across NHS Scotland. (previously Scotland Boost).

Alex TLC X-ALD study - funds received to participate in the Alex TLC X-ALD study.

Rapid Genome Sequencing - funds received for research into the Rapid genome sequencing for the diagnosis of critically ill children in the NHS Genomic Medicine service: Ensuring an equitable and effective parent and patient-centred service.

ATMP - funding received to assist with the Cell and Gene Therapy Catapult at Guys' Hospital.

Action for Access - funds received to help with the dissemination of the messages in the Action for Access report.

Concord - funds received for research on coordination of care in the UK and dissemination of findings.

SWAN UK Scotland - funds received for outreach in Scotland

SWAN UK Cheshire - funds received for outreach events in Cheshire.

Talking about Gene Therapy - funds are restricted to fund workshops with people living with rare and genetic conditions and report on the outcomes.

Patient survey - funds are restricted to implementing and analysing a survey on individuals' experiences of living with rare and genetic condition and disseminating the findings.

Building Rare Resilience - support- funds are restricted to supporting our members with the challenges associated with Covid-19.

Designated funds

Rare Disease Day - funds were set aside by the trustees in previous years to support awareness of rare conditions. During the current year, it was decided that there was no longer any need for the funds to be separated, so the balance remaining has been transferred back to general funds.

Rare Disease UK General Donations - national campaign for people with rare diseases and all who support them, providing a united voice for the rare disease community by capturing the experiences of patients and families. Rare Disease UK is focused on making sure the new UK Rare Diseases Framework is as successful as possible, and to ensure that patients and families living with rare conditions have equitable access to high quality services, treatment and support.

SWAN UK General Donations - the trustees have set aside these funds received as general donations to SWAN UK, to ensure they are spent on activities within the SWAN UK community.

GENETIC ALLIANCE UK LTD
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18 Movement in funds (continued)

For the year ended 31 March 2023

	At 1 April 2022 £	Income £	Expenditure £	Transfers £	At 31 March 2023 £
Restricted funds					
NHS Scotland	-	10,000	(11,183)	1,183	-
Action for Access	703	-	-	(703)	-
Concord	-	6,805	(7,732)	927	-
SWAN UK Wales	17,332	69,817	(65,137)	-	22,012
SWAN UK Scotland	-	1,000	(1,000)	-	-
SWAN UK Cheshire	-	-	(236)	236	-
Wellcome 2023/25	-	80,000	(80,200)	200	-
Talking about Gene Therapy	-	-	(2,300)	2,300	-
Patient survey	-	6,059	(6,059)	-	-
Building Rare Resilience - support	-	21,768	(21,768)	-	-
Robert Luff trust	-	20,000	(20,000)	-	-
Alex TLC X-ALD study	(547)	1,614	(1,615)	548	-
Rapid Genome Sequencing	(1,137)	20,320	(10,506)	-	8,677
ATMP	-	3,580	(6,716)	3,136	-
	<u>16,351</u>	<u>240,963</u>	<u>(234,452)</u>	<u>7,827</u>	<u>30,689</u>
Unrestricted funds					
General funds	55,109	128,036	(128,870)	(8,235)	46,040
Designated funds					
Rare Disease Day	-	102,964	(103,608)	644	-
Rare Disease UK General Donations	65,499	221,831	(271,889)	-	15,441
SWAN UK: General Donations	14,049	48,065	(30,385)	(236)	31,493
	<u>134,657</u>	<u>500,896</u>	<u>(534,752)</u>	<u>(7,827)</u>	<u>92,974</u>
Total funds	<u>151,008</u>	<u>741,859</u>	<u>(769,204)</u>	<u>-</u>	<u>123,663</u>

19 Analysis of net assets between funds

	Restricted Funds £	Unrestricted Designated Funds £	Unrestricted General Funds £	Total £
As at 31 March 2024				
Tangible fixed assets	-	-	5,634	5,634
Bank and cash	12,134	-	73,449	85,583
Other net assets	-	-	(49,371)	(49,371)
	<u>12,134</u>	<u>-</u>	<u>29,712</u>	<u>41,846</u>

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19 Analysis of net assets between funds (continued)

As at 31 March 2023	Restricted Funds £	Unrestricted Designated Funds £	Unrestricted General Funds £	Total £
Tangible fixed assets	-	-	4,698	4,698
Bank and cash	30,689	46,934	63,834	141,457
Other net assets	-	-	(22,492)	(22,492)
	<u>30,689</u>	<u>46,934</u>	<u>46,040</u>	<u>123,663</u>

20 Related party transactions

There are no transactions with trustees or other related parties other than those disclosed as required by the SORP elsewhere in the financial statements.