Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

GENETIC ALLIANCE UK

Financial statements for the year ended 31 March 2023

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Report of the Trustees

For the year ended 31 March 2023

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 2023.

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 230 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

- While these conditions are individually rare, they are collectively common. Taken together, there are around 3.5 million people living with genetic and rare conditions in the UK.
- A genetic condition is caused by a change in an individual's genome. The most common genetic conditions such as sickle cell disease affect around 15,000 people in the UK, with 300 babies born with the condition each year.
- A rare condition affects fewer than 1 in 2,000 people. There are over 6,000 known rare conditions which can take longer to diagnose and treat than more common rare conditions.
- Eight out of 10 rare conditions have a genetic origin. The rarest genetic conditions may affect just one family in the UK, and a handful of people across the globe.
- An undiagnosed genetic condition is known as a 'syndrome without a name' or SWAN condition. Each year around 6,000 children in the UK are born with a genetic condition so rare than it does not yet have a name. This might be because the right test has not been developed to diagnose it, or the genetic cause of the condition has not yet been discovered.
- Genetic, rare and undiagnosed conditions are often life-limiting and life-threatening. Seven out of 10 rare diseases affect children, and sadly more than three out of 10 children with a rare disease 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 educations services to live their lives to the full.

Summary of Annual Performance 2023

During 2022/23 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 230 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.

Our five -year strategy from 2018 to 2023 set out a mission to work with organisations and individuals to ensure that the needs and preferences of people affected by genetic, rare and undiagnosed conditions are recognised, understood and met. You can read our 2018 to 2023 strategy at www.geneticalliance.org.uk/our-strategy.

During 2022/23 we began to review this strategy ready to approve a new five-year strategy that will be launched at our next Annual General Meeting in Autumn 2023. You can find out more about our new strategy on page 13 in ‘The year ahead’.

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.

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. Three out of 10 of our members are micro charities who have free membership (annual income under £10,000). A further five out of 10 of our members are small charities with membership fees of £50 each year (annual income under £250,000).

New members and improved opportunities for engagement

We welcomed 16 new member organisations into Genetic Alliance UK during 2022/23. These are:

British Nuclear Test Veterans Association
CCHS UK (Congenital central hypoventilation syndrome)
CJD Support Network UK
Cure Mucolipidosis
DEBRA
EOS Network - Eosinophilic Diseases Charity
Eyes on the Future
Hereditary Brain Aneurysm Support (HBA Support)
KBG Foundation
Keep Me Breathing
MACS (Microphthalmia, Anophthalmia & Coloboma Support)
Same but Different
Sisters' Hope Foundation
Syngap1
TOFS
Wales Orphan And Rare Lung Disease [WORLD]

During the first part of 2022/23 we hosted 21 weekly Community Check-ins (via Zoom for accessibility) with an average attendance of 20 members. From January 2023, Community Check-ins were replaced by our new monthly Member Briefings and Member Brews.

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

Building Rare Resilience

Over the past year we've delivered the two rounds of the Building Rare Resilience project to Genetic Alliance UK member organisations. Run in collaboration with RareMinds, the course gave staff at

Genetic Alliance UK member organisations the opportunity to take part in 12 weekly sessions that aimed to build their emotional resilience and wellbeing.

Three ‘Graduate Groups’ from previous cohorts of the project also continued to meet regularly, with a group facilitator from Rareminds joining them once a month.

Additionally, four Building Rare Resilience workshops were held in collaboration with two Genetic Alliance UK member organisations, Beacon and Rareminds. Building on the success of the Building Rare Resilience programme, each session focused on a different topic that aimed to help rare community leaders build skills to look after their own mental health while supporting their communities. All four workshops had over 50 sign ups and received overwhelmingly positive feedback with almost 100% of participants confirming that the workshops had been beneficial.

Research projects for members

A commissioned project for Alex TLC gathered views on newborn screening for an X-linked and adult-onset form of leukodystrophy to feed into their advocacy around newborn screening.

A commissioned project for Ataxia UK delivered an evaluation of their volunteer programme InControl through focus groups, and supported them in developing their next member survey.

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

UK Rare Diseases Framework

The UK governments published a UK Rare Diseases Framework in early 2021, which you can find here: https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework. It sets out the commitment of UK governments to improve the lives of people with rare conditions over the next five years. The policy team ensures that our members' voices inform the development of new action plans across the four nations as part of the implementation of the UK Rare Diseases Framework. We've also assisted with the oversight of the UK Rare Diseases Forum and, following feedback from members, we coordinated a constructive criticism letter to ministers requesting improvements to the UK Rare Diseases Forum.

Maximising opportunities to raise awareness on Rare Disease Day 2023

On Rare Disease Day on 28 February, we worked hard with our members to raise awareness of the challenges facing people living with rare conditions and their families. In 2023 we used the high profile of this annual awareness day to focus on one of the key challenges identified by people living with rare conditions and the organisations that support them in the UK Rare Diseases Framework, the need for better coordination of care for people living with life-long and complex rare conditions. Good care coordination can be transformative, but sadly only four out of 10 children and one out of 10 adults have a care plan setting out how their care will be coordinated.

Our work on care coordination has been informed by the well-respected CONCORD (CoOrdinated Care Of Rare Disease) study which outlined a series of models of care coordination. A short animation summarising the CONCORD findings was released for Rare Disease Day 2023, and it can be found alongside the scientific papers at geneticalliance.org.uk/CONCORD.

Highlights from Rare Disease Day 2023 included launching a new policy report, *Coordinating care: learning from the experiences of people living with rare conditions* which can be found at geneticalliance.org.uk/coordinatingcarereport2023. Our members contributed case studies of good practice such as the Alstrom Syndrome Centres of Excellence and the NHS Tuberous Sclerosis Clinics Network. We highlighted the need for better coordination through an article in the Guardian Rare Disease Day supplement which landed in newsagents, and produced a short film highlighting a member case study on good care coordination with support from ITN Business news. We rounded off a busy day by bringing together our members with senior decision makers from the NHS and civil service and Parliamentarians at a Westminster reception focused on care coordination. We hosted similar receptions in Wales, Scotland and online to engage as many people as possible in discussing the need for better care coordination.

Rare Resources Scotland

In 2022/23 we disseminated Rare Resources Scotland to key health and education professionals across the nation. The toolkit is a collection of information guides for families who 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 have been developed and produced by Genetic Alliance UK in collaboration with families and support organisations in Scotland 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.

Rare Resources Cymru

We published Rare Resources Cymru in December 2022 and began to disseminate the resources to key health and education professionals across Wales. The bilingual toolkit is a collection of 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 have been developed and produced by Genetic Alliance UK in collaboration with families in Wales.

Mental health paper

Our research from 2018 was published in a scientific journal in May 2022. The publication of the full survey data in the journal has brought renewed visibility to the importance of mental health care for people with rare conditions and led to new collaborations, such as a bid for one of the new LifeArc rare disease translational centres.

Collaborating with Congenital Anomaly and Rare Disease Information Service (CARIS)

We're working with the Welsh Registry for Rare Diseases to support development of their self-registration service for adults with rare diseases. We have provided feedback on their self-referral forms and linked in member organisations to support piloting this work. We will be supporting future plans for co-production to further develop the service and publicise the opportunity with member networks.

Healthcare Professionals Project – Scotland

In collaboration with support organisations and healthcare professionals in Scotland, Genetic Alliance UK have been undertaking work to improve the visibility of rare conditions in NHS Scotland. This has involved the development of a survey designed to better understand healthcare professional's information and support needs. We have also designed a series of promotional materials, webinars and resources which will be promoted throughout NHS Scotland over the next 24 months. This work features case studies from our community and encourages signposting to our members.

Advanced therapies

Alongside the Cell and Gene Therapy Catapult, we co-chair ATMP Engage which is a monthly multi-stakeholder meeting fostering best practice in involvement and engagement around Advanced Therapy Medicinal Products (ATMPs). We jointly delivered a workshop and report on good communication for advanced therapies which included individuals affected by rare conditions, and the resulting report is hosted on the EuroGCT website. These emerging technologies hold out much promise for rare condition treatments and will continue to be a focus of our policy work.

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

Raising awareness through national and specialist media of issues important to our members

During 2022-23 we've contributed the views of our members about rare conditions, diagnosis and screening and genetic conditions to high-profile stories about the UK Rare Diseases Framework, whole genome sequencing and the new SWAN clinic through a wide variety of media including Bloomberg UK, Learning Disability Today, The Guardian and the British Medical Journal.

Using high profile opportunities to contribute the views of our members

We spoke at a fringe event on rare conditions at the Conservative party conference to raise awareness of the challenges facing our community. We also attended two round-table events hosted by Wes Streeting MP under 'Chatham House rules' to make sure the views of people living with rare and genetic conditions inform the development of Labour's plans for the NHS and social care services.

Providing a platform for patient voice

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. Over the past year we've had a total of seven meetings across the three groups, one parliamentary exhibition in Scotland and we also host genomics cafés every six weeks in Wales. Across all of these events we have invited 16 individuals to share their lived experiences directly with parliamentarians, policy makers and healthcare professionals.

Raising awareness with elected representatives

This year, Genetic Alliance UK had a week-long presence in the Scottish Parliament to engage Members of the Scottish Parliament (MSPs) and raise awareness of the key priorities of the rare, genetic and undiagnosed community. Our exhibition involved sharing the findings of our recent policy reports, highlighting the work of our members and sharing case studies from our community. This exhibition was designed to provide information to support MSPs and their caseworkers to assist them to support their constituents with rare, genetic and undiagnosed conditions.

Influencing legislation

We responded to calls from a group of members to ensure the Down Syndrome Act recognised other genetic conditions with overlapping needs to Down's Syndrome. We formed a coalition group, facilitating engagement with other organisations and staff from the Department of Health and Social Care, to ensure the voices of people living with other genetic conditions were considered in the implementation of the Act.

Ensuring patient voice is involved in decision making and policy development

We continually respond 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 have engaged with members and responded to a total of 21 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 37 preimplantation genetic testing license requests, and responded to a further 31 consultations by UK governments and the NHS on a variety of topics.

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

Encouraging investment in clinical research programmes and clinical genetics services

Science is making great strides forward in genomics. However, people affected by genetic conditions and their families will only benefit from this science if the UK also invests in clinical research programmes and NHS clinical genetics services. We used a high-profile opportunity speaking on a keynote panel at the NHS Genomics Healthcare Summit to raise awareness of the need to make sure 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.

Welsh Rare Disease Action Plan – The SWAN Clinic

In the last year we collaborated with the Welsh Government and RDIG (Rare Disease Implementation Group) to secure funding for the UK's first Syndromes Without a Name clinic in Wales. We coordinated input from the SWAN Cymru Council made up of parents of children affected by undiagnosed genetic conditions to help develop Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) to measure the benefit to patients referred to the clinic.

SWAN UK

Two SWAN UK parent workshops were held in 2022/23 to shape our work. Over 150 new members joined SWAN UK in 2022/23, bringing our membership total up to 3,825. During the year we held eight face-to-face networking events including trips to Blair Drummond Safari Park (70 attendees), the National Space Centre (17 attendees), Chester Zoo (15 attendees), and the Amelia Trust Farm (12 attendees). Four virtual coffee meet ups were held during the year to make our support accessible to everyone, with 18-20 people attending each event. In December we organised a virtual 'Sing-and-Sign-along' event for Christmas attended by 25 SWAN UK families, held in collaboration with Singing Hands. Outreach to raise awareness of the support that SWAN UK can offer continued with introductory emails sent to over 30 NHS genetics services and children's hospices, and SWAN UK posters and covering letters sent to NHS genetics departments across the country.

SWAN UK – Cymru

SWAN UK Cymru has established a Sounding Board, consisting of six SWAN UK members in Wales. The first face-to-face family networking event for members in Wales took place in Spring 2022 with twelve adults and fourteen children attending a bowling event organised by our South Wales parent representative. It was followed by a virtual 'Cuppa and catch up' for parents, visits to Santa's grotto for eight families in December, a SWAN Dads night out in Cardiff, and a Bowling and Burger event for families in March 2023. Outreach to raise awareness of the SWAN UK Cymru project continued throughout the year with presentations to Flying Start Vale of Glamorgan, Wales Gene Park Genomics Café, Kidz to Adultz Exhibition Wales & West, Noah's Ark Children's Hospital, and genetic counsellors at Cardiff's University Hospital of Wales. We have also liaised with the NHS Wales distribution centre who distributed SWAN UK Cymru leaflets in GP packs sent to 380 GP practices in Wales.

Undiagnosed Children's Day 2022

Undiagnosed Children's Day took place on Friday 29 April to raise awareness of the challenges facing children with undiagnosed genetic conditions and their families. We worked with ITN Business news to produce an awareness-raising video that received over 450 views and there were over 1,800 visitors to the SWAN UK Facebook page during April – an increase of 300% from the previous month. We hosted an online disco for thirteen families on the big day, and a virtual SWAN UK Information Day sharing signposting and practical support for families on 5 May which had 61 registered attendees.

Mental health support for the SWAN UK Community

During 2022/23 six SWAN UK couples took part in the SWAN UK Couples Counselling sessions provided by RareMinds. Six SWAN UK members participated in 'Stronger Together' group counselling sessions, a new counselling initiative that has been rolled out as part of the SWAN UK - Cymru project. The Stronger Together project consists of weekly group counselling sessions for a set group of six SWAN UK - Cymru members which are being delivered over a ten-week period. The sessions aim to improve the mental well-being of those taking part as well as forge strong peer-support connections between participants to create a more sustainable support system.

Genomics Delivery Plan for Wales – published in December 2022

Working in partnership with the Wales Gene Park, we continue to engage patients, families, patient organisations and the public in genomics in Wales. We established Genomics Cafés across Wales for members of the public to find out about new advances in genomic medicine. Since the pandemic, the Cafés are now held virtually every six weeks and reach an audience of around 60-200 attendees, including many Genetic Alliance UK member organisations. We also engage young people through quarterly Young People's Genomics Cafés and we have supported Genomics Partnership Wales to develop strong foundations for patient and public involvement and co-production.

We have supported Genomics Partnership Wales to develop strong foundations for patient and public involvement and co-production, with a three-tiered approach established to ensure a broad range of opportunities for patients and the public to help strengthen the quality of genomics output. We have worked to establish the Genomics Sounding Board, made up of 30 people with diverse experiences of rare genetic conditions and cancer testing or diagnosis. Working together, they have developed guiding principles that will serve as the foundation for future delivery; a commitment to communicate clearly with patients and involving them in prioritising deliverables to ensure maximum benefit; to provide high quality inclusive and accessible services with appropriate levels of support, timely diagnoses, appropriate treatment and best care for patients and their families.

Citizens' Jury on Genome Editing of Human Embryos

We recruited 21 individuals from our membership who are directly affected by a rare, genetic condition to take part in a project to establish the community's views on whether the laws on genome editing of embryos should be reconsidered in Parliament. Organised in partnership with Wellcome Connecting Science and Involve, this project resulted in a report listing the recommendations from participants and also a short documentary. These resources are being used to raise awareness to the public and policy makers of the scientific developments in this area, the views of people affected by rare genetic conditions, and the need to engage our community on topics such as these.

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

Raising awareness of the need to start building new screening programmes

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 populations screening programmes. For example, the newborn bloodspot 'heelprick' test given to every newborn baby in the UK currently screens for a maximum of 9 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 have raised awareness of this issue through 'letters to the editor' to national newspapers and senior-level meetings with the Department of Health and NHS.

Highlighting the challenges on the silver screen

One heart-breaking example of where we can do more on newborn screening is Spinal Muscular Atrophy (SMA) where babies can now be given life-saving and life-changing medication, but only if they are identified and treated before symptoms appear and irreversible motor neuron damage is done. Our short film made with ITN Business news to raise awareness of newborn screening for SMA won a bronze 2023 Lens Award and was shortlisted at the 2023 Smiley Charity Film Awards smileycharityfilmawards.com/charities/genetic-alliance-uk.

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

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.

Supporting research on new approaches to genomic screening

We work closely with Genomics England to inform the development of their new research programme focused on whole genome sequencing, the Newborn Screening Programme. Genomics England regularly join our member briefings to keep our community updated on the project's progress, and we sit on their Ethics Working Group. We are exploring how we can best support their new working group on communicating results and onward support, which will meet in 2023/24. This gives us the 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 hope to be 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 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.

The year ahead

2023/24 Business Plan

Genetic Alliance UK's 16 passionate and committed members of staff (12 whole time equivalent posts) continue to work hard to deliver for the genetic and rare community.

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

- 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 our offer to member organisations and delivering it to a high standard.
- Improving our approach to fundraising, income generation and corporate services.
- Launching a new website to improve understanding of what we do and why it matters.
- Clarifying and improving our offer to the SWAN UK community.

We will also implement the recommendations made in our 2021/22 governance review. These include:

- 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 GDPR, health and safety, and safeguarding.
- Amending the Memorandum and Articles of Association in line with best practice for trustee length of service, membership eligibility criteria, and codes of conduct for trustees and members.

We received a vital three-year grant from the Wellcome Trust which started in 2022/23 to help us make Genetic Alliance UK more sustainable. The focus of this work is developing a new strategy, building our fundraising capabilities, and modernising our approach to equality, diversity and inclusion.

New five-year strategy 2024-29

The Board has developed a new five-year strategy for 2024 to 2029. During 2022/23 we held three Board Away Days to develop a draft strategy which involved consultation with members, supporters and funders. The final strategy, which will be launched at the charity's next Annual General Meeting in Autumn 2023, is set out below.

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.

Next steps are to develop an implementation process, timeline and key performance indicators for the new strategy ahead of its launch in Autumn 2023.

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 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.

Albireo
Alexion
Amicus Therapeutics
BioCryst
Biogen
Chiesi
The Arnold Clarke Foundation
CSL Behring
EUSA Pharma
Gilead
Incyte
Janssen
Kyowa Kirin
The Robert Luff Foundation
The National Lottery Community Fund
Novartis
Orchard Therapeutics
P F Charitable Trust
Pfizer
PTC Therapeutics
Roche
Sanofi
Takeda
Topek Southern Ltd (TSL)
Trisomy 9 Mosaic Trust
UCB
Vertex
The 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 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 27. The total income for the year was £741,859 (£713,568 in 2022).

This represents an overall increase of 4%, however, this was not experienced evenly across all sources of income. General fundraising remains challenging, which has emphasized 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 £769,204 (£762,424 in 2022).

This represents less than a 1% 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 42%, membership and engagement at 37%, research at 8% and raising funds at 12%, which means 88% of our spending is on charitable activities.

Surplus/deficit

Our final financial position for the year across all funds is a deficit of £27,345 (deficit of £48,856 in 2022).

This is comprised of a deficit of £41,483 on unrestricted funds and a surplus of £14,338 on restricted funds.

Reserves policy

Total reserves at the end of the financial year are £123,663 (£151,008 in 2022).

This is made up of restricted reserves of £30,689 (£16,351 in 2022) and unrestricted reserves of £92,974 (£134,657 in 2022).

The change in reserves is due to the in-year surplus and 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

The financial year ended 31 March 2023 was a challenging one for Genetic Alliance UK from an operational and financial perspective, as the cost of living crisis impacted on the charity, our members and our beneficiaries.

The Executive Team have demonstrated their ability to lead and manage in a challenging environment. However, it is clear that financial risk still remains and the year ahead will require a continued focus on fundraising and continued cost consciousness.

As noted on page 30 the Board of Genetic Alliance UK are mindful that the charity is 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, indicates that the charity will break even for the year ending 31 March 2024 and that adequate liquid resources will continue to be available to fund the activities of the charity for the foreseeable future.

We are pleased that the Auditors have endorsed this view that the charity remains a going concern and we will work to ensure that it continues to be there for all those who need it.

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 plan to update the Memorandum and Articles 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

Trustees are elected by the membership. 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 plan to recruit up to four new trustees to increase the independence and diversity of the Board.

Governance and organisational management

Trustees held four Board meetings in the year ending 31 March 2023, where they reviewed the charity's performance and determined and approved operating plans and budget.

During 2022/23 Trustees also held three Board Away Days to develop a draft strategy which we consulted on with members, supporters and funders. The final strategy will be launched at the charity's next Annual General Meeting in Autumn 2023.

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 four times in the year. 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 plan to introduce a new People and Policies (P&P) committee chaired by a nominated Trustee which 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 issues such as GDPR, health and safety, and safeguarding.

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.

Fundraising

Genetic Alliance UK undertakes most of its fundraising activities in-house, but used a consultant during 2022/23 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. During 2022/23 we updated our policy on working with industry to set out clear principles and guidance for how we work with the life-sciences industry: geneticalliance.org.uk/policies/working-with-industry-policy/.

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

Creative Works, 7 Blackhorse Lane, London E17 6DS

Trustees

Ms Gloria Clark
Ms Phillippa Farrant
Miss Sara Hunt
Dr Celine Lewis (resigned May 2022)
Mr Neil McClements
Mrs Sue Millman (Vice Chair)
Mrs Elizabeth Porterfield (Chair)
Mr David Ramsden (Treasurer)
Dr Susan Walsh (completed terms as trustee September 2022)
Mrs Julie Wooton (resigned February 2023)
Dr Sarah Wynn

Board observer

Robin Nott

Chief Executive Officer

Nick Meade and Lauren Roberts (Interim Chief Executives until June 2022)
Louise Fish (joined July 2022)

Senior Management Team

Dr Amy Hunter, Nick Meade, Lauren Roberts (left July 2022), Mary Edwards (joined February 2023)

Auditors

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

Management accountant

Fiona Bevan Financial Management

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 27 July 2023 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

Opinion

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2023 set out on pages 27 to 44 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 2023, 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 22 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 company and the industry in which it operates and considered the risk of acts by the charity 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 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.

We also communicated relevant identified laws and regulations and potential fraud risks to all engagement team members and remained alert to any indications of fraud or noncompliance with laws and regulations throughout the audit.

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 auditor's 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.

Jennifer Pope

Jennifer Pope (senior statutory auditor)
for and on behalf of

Nyman Libson Paul LLP
Chartered Accountants
Registered Auditors
124 Finchley Road
London
NW3 5JS
Date: 27 July 2023

GENETIC ALLIANCE UK LTD

STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME AND EXPENDITURE ACCOUNT)

YEAR ENDED 31 MARCH 2023

	Note	**Unrestricted Funds £**	**Restricted Funds £**	**Total Funds 2023 £**	Total Funds 2022 £
Income from:					
Donations and legacies	**2**	457,074	232,950	690,024	657,454
Charitable activities	**3**	43,717	8,013	51,730	56,114
Investments		105	-	105	-
Total income		500,896	240,963	741,859	713,568
Expenditure on:					
Raising funds	**4**	94,391	-	94,391	95,416
Charitable activities	**5**	440,361	234,452	674,813	667,008
Total expenditure		534,752	234,452	769,204	762,424
Net income/(expenditure)	**8**	(33,856)	6,511	(27,345)	(48,856)
Transfers between funds	**18**	(7,827)	7,827	-	-
Net movement in funds		(41,683)	14,338	(27,345)	(48,856)
Total funds at start of year	**18**	134,657	16,351	151,008	199,864
Total funds at end of year	**18**	92,974	30,689	123,663	151,008

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 30 to 44 form part of these financial statements
See note 11 for fund-accounting comparative figures

GENETIC ALLIANCE UK LTD

BALANCE SHEET

AS AT 31 MARCH 2023

Company number: 05772999

	Note	**2023** **£**	2022 £
Fixed assets			
Tangible assets	**12**	4,698	992
		4,698	992
Current assets			
Debtors	**13**	53,368	66,149
Cash at bank and in hand		141,457	199,282
		194,825	265,431
Liabilities			
Creditors : amounts falling due within one year	**14**	(75,860)	(115,415)
Net current assets		118,965	150,016
Total assets less current liabilities		118,965	150,016
Net assets		123,663	151,008
FUNDS			
Unrestricted funds			
General funds	**19**	46,040	55,109
Designated funds	**19**	46,934	79,548
Restricted funds	**19**	30,689	16,351
Total funds		123,663	151,008

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 27 July 2023 and are signed on their behalf by:

Elizabeth Porterfield
Chair of Trustees

The notes on pages 30 to 44 form part of these financial statements

GENETIC ALLIANCE UK LTD

CASH FLOW STATEMENT

YEAR ENDED 31 MARCH 2023

	Note	**2023** **£**	2022 £
Net cash inflow from operating activities	**15**	(53,457)	(39,336)
Non-operational cash flows:			
Investing activities			
Payments for tangible fixed assets		(4,368)	(1,278)
		(4,368)	(1,278)
Net cash inflow/(outflow) for the year	**16**	(57,825)	(40,614)

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 30 to 44 form part of these financial statements

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) (second edition January 2019) and the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the *Companies Act 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 2022/23 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 the careful planning and budgeting.

These circumstances resulted in an unrestricted fund deficit for the year of c £33k compared to a deficit for the previous year of c £24k. Unrestricted free reserves (general and designated funds) stand at approximately £92k as at 31 March 2023 and these reserves continue to provide a buffer for the charity.

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, indicates that the Charity will break even for the year ending 31 March 2024 and that adequate liquid resources will continue to be available to fund the 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.

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.

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.

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 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
Grants from Government			
National Lottery funding	-	69,817	69,817
Scottish Government	-	10,000	10,000
Other grants received	3,930	2,000	5,930
Donations through fundraising:			
Online donations	48,472	-	48,472
	457,074	232,950	690,024

2 Income from donations and legacies *(continued)*

Prior year

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Donations from supporters	278,998	150,899	429,897
Legacies received	2,000	-	2,000
Robert Luff Trust	-	20,000	20,000
Wellcome Trust	5,000	-	5,000
University College London	-	5,845	5,845
Edward Gostling	4,689	-	4,689
Hugh Fraser	6,000	-	6,000
Great Ormond Street Hospital	-	10,318	10,318
Grants from Government			
National Lottery funding	-	72,812	72,812
Scottish Government	-	9,961	9,961
Covid Job Retention Scheme fund	6,584	-	6,584
Other grants received	11,308	4,000	15,308
Donations through fundraising:			
Online donations	69,040	-	69,040
	383,619	273,835	657,454

3 Income from: Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2023 £
Consultancy work	43,717	8,013	51,730
	43,717	8,013	51,730

Prior year

	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Consultancy work	56,114	-	56,114
	56,114	-	56,114

4 Expenditure on: Raising funds

		Total Funds 2023 £	Total Funds 2022 £
Staff costs, including consultancy work		85,432	87,483
Fees		1,493	1,438
Other direct costs		181	-
Support costs	(Note 6)	7,285	6,495
		94,391	95,416

5 Expenditure on Charitable activities

	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
	358,227	316,586	674,813

Prior year	Direct Costs £	Support Costs (Note 6) £	Total Funds 2022 £
Membership and Engagement	226,973	65,296	292,269
Policy work	173,533	127,939	301,472
Research	34,486	38,781	73,267
	434,992	232,016	667,008

£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 year. £112,089 of support costs and £122,363 of direct costs relates to restricted funds spent during the year.

£176,390 of the above support costs in notes 4 and 5 and £276,026 of direct costs relate to unrestricted funds spent during the prior year. £62,121 of support costs and £235,927 of direct costs relates to restricted funds spent during the prior year.

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 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
		7,285	316,586	323,871

Prior year		**Raising Funds £**	**Charitable Activities £**	**Total 2022 £**
Staff costs		-	127,654	127,654
Communications		352	2,947	3,299
Office and admin costs		6,143	51,373	57,516
Travel		-	2,369	2,369
Finance costs		-	772	772
Professional fees		-	35,801	35,801
Governance costs	(Note 7)	-	11,100	11,100
		6,495	232,016	238,511

7 Governance costs

	Total Funds 2023 £	Total Funds 2022 £
Auditor's fees - for audit services	9,000	8,100
Accounts review	3,060	3,000
	12,060	11,100

8 Net income/(expenditure) for the year

This is stated after charging:

	2023	2022
	£	£
Auditor's remuneration - for audit services	9,000	8,100
Trustees' travel expenses (3 trustees, 2022: 2 trustees)	2,325	884
Depreciation	662	286

No Trustee received any remuneration during the year.

9 Staff costs and numbers

The aggregate payroll costs were:

	2023	2022
	£	£
Wages & salaries	499,662	446,757
Social security costs	51,212	41,839
Pension contributions	28,421	25,283
Redundancy costs	-	8,338
	579,295	522,217

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

	2023	2022
Between £60,001 and £70,000	-	1
Between £70,001 and £80,000	1	-

The average weekly number of employees during the year was 16 (2022: 17), 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 £173,181 (2022: £181,356).

10 Taxation

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

11 Statement of Financial Activities comparative figures

For the year ended 31 March 2022	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £
Income from:			
Donations and legacies	383,619	273,835	657,454
Charitable activities	56,114	-	56,114
Total income	439,733	273,835	713,568
Expenditure on:			
Raising funds	95,416	-	95,416
Charitable activities	368,960	298,048	667,008
Total expenditure	464,376	298,048	762,424
Net income/(expenditure)	(24,643)	(24,213)	(48,856)
Transfers between funds	(1,430)	1,430	-
Net movement in funds	(26,073)	(22,783)	(48,856)
Total funds at start of year	160,730	39,134	199,864
Total funds at end of year	134,657	16,351	151,008

12 Tangible fixed assets

	Office equipment £	Total £
Cost or valuation		
At 1 April 2022	1,278	1,278
Additions	4,368	4,368
At 31 March 2023	5,646	5,646
Depreciation		
At 1 April 2022	286	286
Charge for the year	662	662
At 31 March 2023	948	948
Net book value		
At 31 March 2023	4,698	4,698
At 31 March 2022	992	992

13 Debtors

	2023 £	2022 £
Due in less than one year:		
Trade debtors	46,325	47,136
Prepayments and accrued income	6,383	17,813
Other debtors	660	1,200
	53,368	66,149

14 Creditors: amounts falling due within one year

	2023 £	2022 £
Trade creditors	4,333	6,165
Social security and other taxes	14,298	20,617
Other creditors	7,465	4,320
Accruals and deferred income	49,764	84,313
	75,860	115,415

15 Reconciliation of net movement in funds to net cash inflow from operating activities

	2023 **£**	2022 £
Statement of Financial Activities: Net movement in funds	(27,345)	(48,856)
Depreciation	662	286
(Decrease)/increase in creditors: current liabilities	(39,555)	(50,990)
Decrease / (increase) in debtors	12,781	60,224
Net cash inflow/(outflow) from operating activities	(53,457)	(39,336)

16 Analysis of changes in cash during the year

	2023 **£**	2022 £	**Change** **£**
Cash at bank and in hand	141,457	199,282	(57,825)

	2022 **£**	2021 £	**Change** **£**
Cash at bank and in hand	199,282	239,896	(40,614)

17 Analysis of changes in net debt

	1 April 2022 £	Cashflow Movements £	31 March 2023 £
Cash at bank and in hand	199,282	(57,825)	141,457
	199,282	(57,825)	141,457

Prior year	1 April 2021 £	Cashflow Movements £	31 March 2022 £
Cash at bank and in hand	239,896	(40,614)	199,282
	239,896	(40,614)	199,282

18 Movement in Funds

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	-
	16,351	240,963	(234,452)	7,827	30,689
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
	134,657	500,896	(534,752)	(7,827)	92,974
Total funds	151,008	741,859	(769,204)	-	123,663

Fund descriptions
Restricted funds

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

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.

RD PSPs - funds received for establishing, and dissemination of, research priorities for mitochondrial disease.

SWAN UK: Dads' Summit - funds received for outreach for dads of children affected by undiagnosed genetic conditions.

18 Movement in funds *(continued)*

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 Scotland - funds received for outreach in Scotland
SWAN UK Cheshire - funds received for outreach events in Cheshire.
Wellcome 23-25 - funding received from the wellcome trust for strategy development, implementation of a quality and diversity review and fundraising support.
Building Rare Resilience - This was the second instalment of restricted funding from the National Lottery Covid-19 emergency fund for the Building Rare Resilience project.

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.
Rare Resources - funds are restricted to the development and dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions.
Building Rare Resilience - support - funds are restricted to supporting our members with the challenges associated with Covid-19.
Robert Luff trust - funds received from the trust for undertaking research.
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.
Rare Disease Day - funds received to help with the costs of putting on our annual Rare Disease Day**.**
ATMP - funding received to assist with the Cell and Gene Therapy Catapult at Guys' Hospital

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.

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.

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.

18 Movement in funds *(continued)*

For the year ended 31 March 2022

	At 1 April 2021 £	Income £	Expenditure £	Transfers £	At 31 March 2022 £
Restricted funds					
Scotland Boost	1,309	5,961	(7,999)	729	-
Action for Access	18,401	-	(18,401)	-	-
Concord	-	5,845	(5,142)	-	703
RD PSPs	5,442	-	(6,143)	701	-
SWAN UK: Dads' Summit	-	4,749	(4,749)	-	-
SWAN UK Wales	9,928	54,286	(46,882)	-	17,332
Building Rare Resilience	-	20,026	(20,026)	-	-
Talking about Gene Therapy	4,054	-	(4,054)	-	-
Patient survey	-	8,066	(8,066)	-	-
Rare Resources	-	7,054	(7,054)	-	-
Building Rare Resilience - support	-	59,232	(59,232)	-	-
Robert Luff trust	-	20,000	(20,000)	-	-
Alex TLC X-ALD study	-	-	(547)	-	(547)
Rapid Genome Sequencing	-	10,318	(11,455)	-	(1,137)
Rare Disease Day	-	78,298	(78,298)	-	-
	39,134	273,835	(298,048)	1,430	16,351
Unrestricted funds					
General funds	62,409	130,096	(170,833)	33,437	55,109
Designated funds					
Rare Disease Day	34,867	-	-	(34,867)	-
Rare Disease UK General Donations	63,454	250,241	(248,196)	-	65,499
SWAN UK: General Donations	-	59,396	(45,347)	-	14,049
	160,730	439,733	(464,376)	(1,430)	134,657
Total funds	199,864	713,568	(762,424)	-	151,008

19 Analysis of net assets between funds

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)
	30,689	46,934	46,040	123,663

19 Analysis of net assets between funds (continued)

As at 31 March 2022	Restricted Funds £	Unrestricted Designated Funds £	Unrestricted General Funds £	Total £
Tangible fixed assets	-	-	992	992
Bank and cash	16,351	79,548	103,383	199,282
Other net assets	-	-	(49,266)	(49,266)
	16,351	79,548	55,109	151,008

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.