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

GENETIC ALLIANCE UK ltd

Annual Report and Financial Statements for the year ended 31 March 2025

Report of the Board of Trustees

For the year ended 31 March 2025
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 2025.

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).

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Cover photograph by Dylan Lombard as part of his submission to the ‘More than you can imagine’ anthology

Genetic Alliance UK – contactus@geneticalliance.org.uk – geneticalliance.org.uk
Registered charity numbers: 1114195 and SC039299
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Welcome from the Chair

This year marked a new chapter for Genetic Alliance UK. In April 2024, we began implementing our new five-year strategy – a far-reaching plan to ensure the ambitions of the UK Rare Diseases Framework that matter most to people living with genetic, rare or undiagnosed conditions drive action and improvement across the four nations.

It has also, again, been a year of change and challenge for GA-UK, and one of success. Early on, we said a fond farewell to our CEO, Louise Fish, after two years of impactful leadership. The ensuing months of transition saw the appointment of Louise's successor, completing an organisational restructure alongside a reduction of the team in recognition of the financial challenges we continued to face this year. I am glad to say that these steps, while difficult but essential to strengthen our financial sustainability, were successful. As always, the Board is grateful to our staff, past and present, for their resilience and commitment, which ensured we continued to deliver for our community without interruption.

Throughout the year our priority has been to put our community's voice at the heart of everything we do. Across the UK, we amplified the lived experiences of people with rare conditions in policy, practice, and research – working with government, research funders, the NHS, industry, and academia to secure change. I am particularly pleased to highlight significant progress in:

- **Supporting undiagnosed families** – through SWAN UK, we expanded our reach to 160 individuals and 153 families, delivered inclusive events across England, and launched new resources for professionals to better support children with suspected genetic conditions
- **Shaping national policy** – taking a leading role in implementing the UK Rare Diseases Framework, successfully influencing newborn screening reform, access to medicines, and genomic service delivery.
- **Driving high-profile campaigns** – our 'More than you can imagine' Rare Disease Day campaign brought together creative voices from over 50 conditions, reaching more than a million people.
- **Delivering practical resources** – launching our new 'Seeking a Rare Diagnosis' guides, co-produced with families, clinicians, and member charities.
- **Strengthening public engagement** – reaching thousands through events, workshops, and forums from schools to parliaments.

This work has been possible thanks to the dedication of our staff, trustees, volunteers, and our growing membership of over 220 charities and support groups.

I must also record thanks to our funders and partners, whose investment in our work has been invaluable and has extended and amplified our reach and impact.

At the very end of the year and as we look ahead to 2025–26, we will continue to focus on seeking to secure a renewed UK Rare Diseases Framework, improving diagnosis and care pathways, and ensuring our community's voice shapes the future of healthcare innovation. We will do this as we also look forward to appointing a new Chief Executive following the resignation of Mark Flannagan in February 2025. This is an opportunity to bring forward a period of calm, commitment and sustainability as we now see continuing improvements in our financial position and with the prospect of even greater drive, enthusiasm and success in our next chapter.

I am delighted to be able to continue to play my part alongside all of our community. Together we are turning rare experiences into lasting change.

Elizabeth Porterfield, MBE
Chair of the Board of Trustees

Genetic, Rare and Undiagnosed Conditions in numbers

- 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
- 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
- Seven in 10 rare conditions affect children
- More than 3 out of 10 children with a rare condition die before their fifth birthday

Objective and Aims

Genetic Alliance UK (the ‘charity’) is an alliance of over 220 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 genetic, rare and undiagnosed conditions.

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.

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.

In April 2024 Genetic Alliance UK began the implementation of our new five year Strategy for 2024 to 2029.

The development of our new strategy involved consultation with members, supporters and funders. The strategy was launched at the charity’s Annual General Meeting in Autumn 2023. This is the first financial year where we have developed a business plan and budget setting out our work for the coming year based on the aims and objectives in our new strategy.

Genetic Alliance UK’s Strategy 2024-29

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 Diseases Framework that matter most to people living with genetic and rare conditions drive action across the four nations.

Our objectives to deliver on this strategy (how we will do it):
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)

- 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 Diseases Framework that matter most.
- Monitoring and evaluating implementation of the UK Rare Diseases 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)
We believe we are people-centred, collaborative, inclusive, influential, evidence-led, knowledge-generating and independent.

Highlights and Impact 2024–25

This year we have:

Influenced policy at the highest level

- Represented the rare condition community at the UK Rare Diseases Framework Board and in devolved implementation groups.
- Contributed to over 25 national and international advisory boards, including the UKNSC Blood Spot Task Group, Genomics Leadership Group (Scotland), and Genomics Partnership Wales Programme Board.
- Achieved references to our work in ministerial speeches in Wales, England, and Scotland on Rare Disease Day 2025.
- Brought our community's perspectives to the design of the 10 Year Health Plan for England.

Delivered high-profile campaigns

- Brought genetic, rare and undiagnosed conditions to the attention of candidates in the General Election.
- Rare Disease Day 2025 – 'More than you can imagine', anthology of over 60 creative submissions representing more than 50 conditions; launched alongside a policy report calling for renewal of the UK Rare Diseases Framework.
- Hosted parliamentary receptions in Westminster, Holyrood, and Senedd, plus a UK-wide virtual event – engaging over 400 stakeholders.
- Media reach of over 1.1 million through national and regional outlets.

Strengthened patient voice

- Expanded our Patient Empowerment Group (PEG) to more than 30 active members, contributing to advocacy on rare condition data registration, equitable access to medicines, and mental health policy.
- Supported the England Rare Disease Action Plan Patient Advisory Group, providing lived experience perspectives on service delivery.

Produced practical resources

- Launched the Seeking a Rare Diagnosis (SARD) guides for adults and children – co-produced with clinicians, patients, and carers.
- Made guides available online, in print, and as co-brandable PDFs for member organisations.

Advanced research and innovation

- Completed an international review of newborn screening decision-making in 10 countries.
- Partnered with LifeArc Translational Centres for Rare Disease to develop a PPIE strategy and policy priorities.

Engaged the public

- Through our collaboration with the Wales Gene Park, delivered over 70 events reaching 3,000+ people – including public talks, careers sessions, science festival activities, and Genomics Cafés.
- Awarded 'Best Engagement Stand' at the Health and Care Research Wales Annual Conference.

Built stronger partnerships

- Supported our member charities through member briefings, peer networking, and resource-sharing.
- Collaborated with Neurological Alliance, Specialised Healthcare Alliance, RareMinds, Beacon, Medics4RareDiseases, and ATMP Engage on joint campaigns and events.

Parliamentary Under Secretary of State Ashley Dalton MP, speaks at the Westminster Rare Disease Reception, February 2025

Patient Voice at the Centre

Placing the voice of people living with genetic, rare and undiagnosed conditions at the heart of decision-making is at the core of our mission. This year, our Patient Empowerment Group (PEG) has been central to shaping policy, research, and practice.

Expanding our influence

PEG grew to over 30 members, bringing together expert representatives from across the UK – including those holding formal patient voice roles in the implementation of the UK Rare Diseases Framework. Members contributed perspectives grounded in lived experience on priorities such as:

- Data collection and sharing through national rare disease registration services - with representatives of National Disease Registration Service consulting PEG.
- Equitable access to medicines – influencing NICE and MHRA processes.
- Care coordination – advising on national Quality Standard development for rare conditions.

Shaping national frameworks

- Presented cross-nation recommendations on collaboration and expansion of action plan commitments to the England Rare Disease Action Plan Delivery Group.
- Advised on devolved action plans in Wales and Scotland, ensuring shared learning between nations.
- Informed the NHS England 10-Year Plan consultation via a dedicated rare condition workshop in collaboration with Association of Medical Research Charities.

Ensuring representation in key policy areas

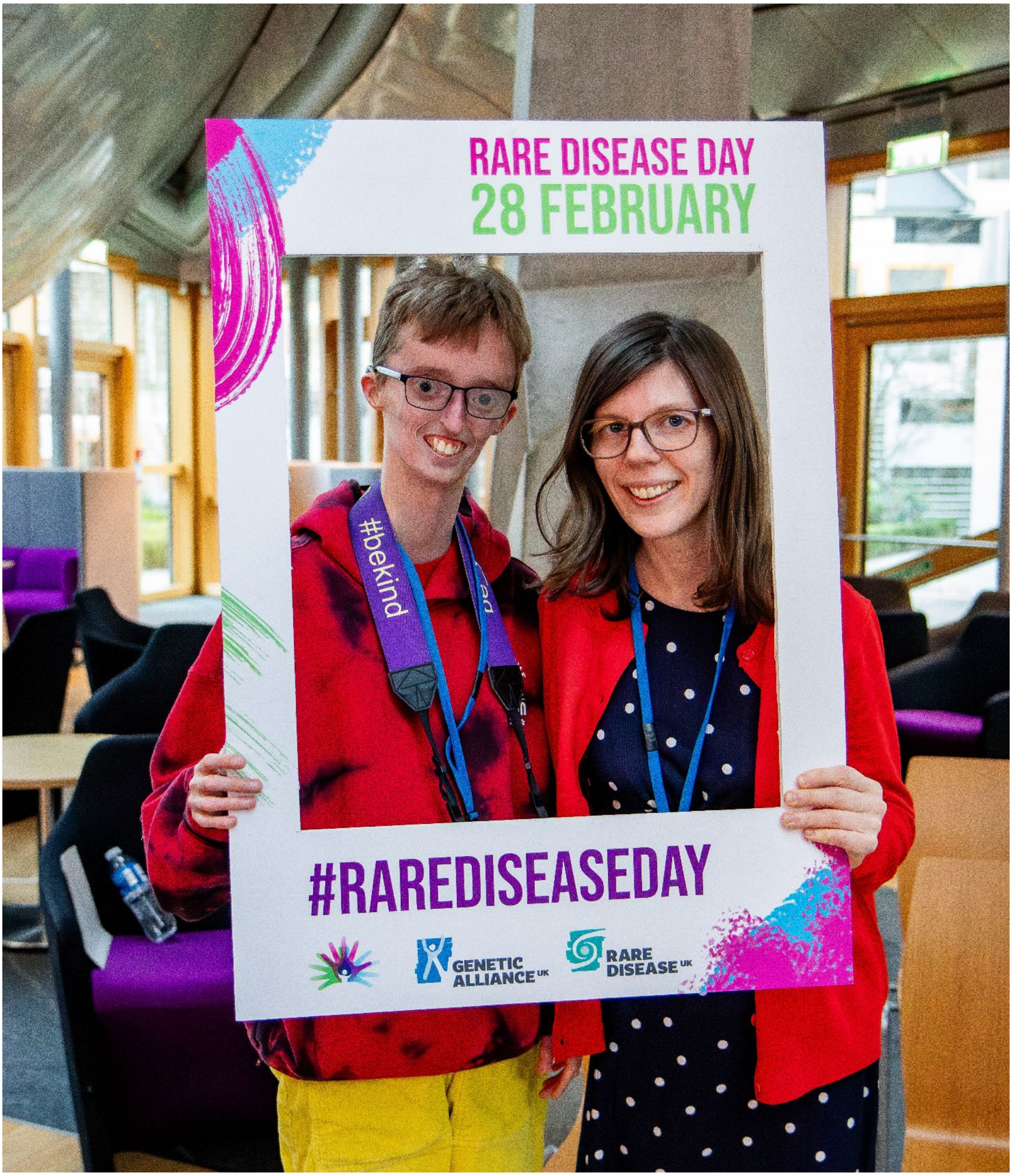
- Contributed to newborn screening reform through the UKNSC Blood Spot Task Group and consultation on our international review recommendations.
- Engaged with the Generation Study on newborn genomic sequencing, providing feedback on materials and process from the community's perspective.

Building capacity and connection

- Five PEG meetings were held in 2024–25, supplemented by working group activity between sessions.
- Members were supported with policy updates, training opportunities, and peer discussion space.
- Collaboration with the Northern Ireland Rare Disease Partnership ensured input from all four nations.

> *'Thanks again for all your and GAUK's support. The team have all been a tremendous support to us specifically and indispensable voice in the sector more broadly.'* – PEG member

Through PEG and our wider networks, we are building a confident, informed, and connected community that can influence the policies and practices that shape lives.



Dylan Lombard and Kimberley Stewart Beasley, speakers at the Holyrood Rare Disease Day Reception, March 2025

Campaigns and Advocacy

Our campaigns are the most visible part of our work – raising awareness, building understanding, and driving the political will for change. This year, our advocacy work has spanned the UK and reached far beyond our borders.

Rare Disease UK
Rare Disease UK, our long-running campaign, continues to unite the voices of people living with genetic, rare and undiagnosed conditions. Through research, policy engagement, and creative storytelling, we've amplified the experiences of our community in ways that connect directly with decision-makers.

Rare Disease Day 2025 – 'More than you can imagine'
This year's theme celebrated the creativity, resilience, and diversity of the rare condition community while underlining the urgent need for continued policy action.

- Anthology and Policy Report – Over 60 creative submissions from people aged 9 to 71, representing more than 50 conditions, were brought together in an anthology. Alongside it, we launched a policy report calling for a renewed UK Rare Diseases Framework.
- Parliamentary Receptions – Hosted events in Westminster, Holyrood, and the Senedd, plus a UK-wide virtual reception, reaching more than 400 attendees in total.
- High-profile launches – England's 2025–26 Rare Diseases Action Plan was launched at our Westminster reception by Ashley Dalton MP, Parliamentary Under-Secretary of State for Health and Social Care.
- Media and Public Engagement – Coverage in BBC, Telegraph, Metro and specialist media, with an estimated reach of 1.1 million.
- Creative impact – Exhibitions of anthology submissions at parliamentary events, sharing the personal stories behind the policy priorities.

> *'Great to hear talks from people who battle rare conditions and to see people who can make change in the field showing real passion for our community.'* – themyasthenicmedic, Holyrood reception attendee, instagram

Shaping National and Devolved Policy
With the 10 Year Health Plan for England on the horizon:

- We ensured that the voices of the 3.5 million people living with genetic, rare, and undiagnosed conditions remained central to the national conversation around the NHS 10-Year Plan for England, calling urgently for explicit recognition of their complex needs within the plan.
- We co-hosted a workshop with the Association of Medical Research Charities to perform a deep-dive into rare condition research opportunities that should be captured in the plan.

Contributions to the ‘More than you can imagine’ anthology, by (clockwise from top left), Marian Adejokun, Matilda Tumim, and retiring Trustee, Phillippa Farrant.

We worked continuously to influence policy in all four nations:

- Re-established the All-Party Parliamentary Group on Genetic, Rare and Undiagnosed Conditions and delivered associated meetings.
- Led a newborn screening parliamentary drop-in event in Scotland and delivered the 'How Decisions Are Made' Scottish project.
- Issued open letters to NHS England and worked collaboratively with the Specialised Healthcare Alliance and National Voices to secure our community's needs in the merger between NHS England and the Department of Health and Social Care.
- Delivered targeted engagement in Wales and Scotland, through stakeholder forums, policy submissions, parliamentary and public events.
- Continued our collaboration with the Northern Ireland Rare Diseases Partnership.
- Worked with Department of Health and Social Care on the Down Syndrome Act, to ensure the resulting guidance is fair to all people affected by genetic conditions.

Jeremy Miles MS, Cabinet Secretary for Health and Social Services (second from right), with fellow speakers (from left) Anthony Pemberton, Dr Jamie Duckers, Rhiannon Edwards, Emily Taylor, John Griffiths MS and Nick Meade, at the Welsh Rare Disease Day reception in February 2025

We also ensured our members' voices were heard in key policy decisions:

- Responding to consultations – we submitted 14 consultation responses on behalf of our members to bodies including the UK National Screening Committee, Science, Innovation and Technology Committee, NICE, NHS England, Department for Work and Pensions,

Department of Health and Social Care, Medicines and Healthcare Products Regulatory Authority (MHRA), Welsh Government, NHS Wales, Advanced Therapy Wales, and the World Health Organization.
- Providing expert evidence – we supplied 43 condition-specific statements to the Human Fertilisation and Embryology Authority (HFEA) to support decision-making on preimplantation genetic testing.

> *'The Committee wanted to pass their thanks on for these statements. They found your statement for DGI1 particularly helpful and they said this helped sway their decision to authorise this condition.'* – Human Fertilisation Embryology Authority on behalf of their Statutory Approvals Committee

International Collaboration
As members of EURORDIS and Rare Disease International, we continued to ensure UK perspectives shape global rare condition policy and practice. This included chairing a plenary session at the European Conference on Rare Diseases in Brussels and contributing to the International Consortium on Newborn Sequencing.

Our campaigns this year have demonstrated that combining evidence, creativity, and strategic engagement is the most effective way to achieve lasting change.

Research and Innovation

Research is key to transforming diagnosis, treatment, and care for people living with genetic, rare and undiagnosed conditions. Our role is to ensure that this research is shaped by the needs, priorities, and experiences of our community.

Newborn Screening: International Review
In 2024–25, we worked on a major international review of how newborn screening decisions are made in 10 countries. This work included:
- Interviews with experts in genomics, ethics, policy, and patient advocacy, both in the UK and overseas.
- Analysis of decision-making frameworks, criteria, and governance structures.

These findings will inform our forthcoming UK policy report and campaign, aiming to modernise and expand newborn screening in line with international best practice.

Generation Study
We supported Genomics England's Generation Study, which explores the potential for genomic sequencing in newborns, by:
- Reviewing participant materials for clarity and accessibility.
- Advising on approaches to consent and family engagement.

- Connecting study leaders with lived experience networks to test design and communication strategies.

We are participants in the Generation Study Evaluation led by UCL. Our work is focused on answering:

- How prepared are patient organisations to support families taking part in genomic newborn screening?
- What impact do patient organisations think genomic newborn screening will have on the families they support now and in the future?

Participants at the Generation Study Parliamentary Drop In session hosted by Liz Twist MP, January 2025

LifeArc Translational Centres for Rare Disease

As co-leads for patient and public involvement, policy, and communications workstreams, we:

- Developed a PPIE strategy to guide involvement across multiple centres.
- Facilitated knowledge-sharing between research teams and patient groups.
- Helped shape policy messages to maximise the translational impact of rare condition research.

International Engagement

Our involvement in the International Consortium on Newborn Sequencing (ICoNS) and Screen4Care ensured that UK patient perspectives were included in global discussions on newborn genomic sequencing and rare condition detection. We chaired a plenary session at the European Conference on Rare Diseases in Brussels on the topic of screening.

Why this matters

Embedding patient voice in research means better-designed studies, more relevant outcomes, and faster translation of findings into real-world benefits. Our work in 2024–25 has laid the groundwork for research that not only advances science but also meets the real needs of our community.

Membership and Partnerships

Our members are at the heart of everything we do. In 2024–25, we worked with more than 220 charities, support groups, and patient organisations across the UK, building connections, sharing resources, and delivering joint campaigns.

Our membership is as diverse as the community we serve. From large, UK-based charities with global reach to small, ultra-rare organisations run from kitchen tables, and everything in between. Each brings unique knowledge, priorities, and perspectives. We work to ensure that all of our members, regardless of size or resource, have a platform and a voice. This diversity strengthens our alliance and ensures that our work reflects the breadth of needs and experiences across the UK rare disease space.

Supporting and Connecting Members

- Monthly Member Meetings – nine sessions with expert guest speakers covering topics from newborn screening to research with an average of 35 attendees per session.
- We welcomed 17 new members to Genetic Alliance UK.
- Co-branded resources – Provided templates and materials for our 'Seeking a Rare Diagnosis' guides, enabling smaller organisations to offer tailored information to their communities.
- Campaign toolkits – Equipped members with materials for Rare Disease Day, including social media assets, exhibition resources, and template press releases.

Collaborating for Change

- Partnered with Neurological Alliance, Specialised Healthcare Alliance, RareMinds, Beacon, Medics4RareDiseases on joint campaigns, events, and advocacy.
- Worked with the Charity Medicines Access Coalition to improve equity in treatment availability.
- Collaborated with LifeArc on translational research priorities and public involvement.

Strength in Partnership
These connections multiply our impact. By sharing expertise, pooling resources, and aligning messages, we ensure that the needs and priorities of people living with genetic, rare and undiagnosed conditions remain visible and high on the agenda.

SWAN UK – Supporting families without a diagnosis

SWAN UK (syndromes without a name) is the only dedicated support network in the UK for families of children and young adults with undiagnosed genetic conditions. In 2024–25, our work focused on rebuilding community connections, expanding reach, and delivering tailored information and support.

Strengthening community connections

Over the past year, we re-engaged families across England through in-person and online events:

- Yorkshire Wildlife Park – 17 families joined a day of connection and shared understanding.
- Worcester Snoezelen – An inclusive play and sensory centre where families felt welcomed and understood.
- Dads' Meet-up – Creating space for fathers to connect and share experiences.
- Undiagnosed Children's Day – Celebrating community and raising awareness nationwide.

> "We absolutely loved it. Looking forward to another meet-up." – Yorkshire Wildlife Park attendee
> "There are so few places that make us feel welcome… it was really nice to feel understood." – Worcester Snoezelen attendee

Sharing information and building confidence

- Virtual information events – In partnership with Contact, we delivered three online sessions (plus two planned for July and October 2025) covering topics from benefits to navigating education support.
- Primary school transitions workshop – 100% of attendees reported feeling better informed and more confident, with 75% feeling less isolated.
- Parent Rep workshop – Strengthening the skills and connections of our volunteer representatives.

Developing professional resources

To improve support for families at the earliest stages:

- Commissioned short films featuring a geneticist and a nurse, aimed at helping professionals understand the needs of undiagnosed families.
- Designed an infographic for health visitors with practical tips for supporting children with suspected genetic conditions.

Expanding our reach

- We now support 160 individuals and 153 families, with 29% living in rural areas (up from 16%). Through targeted outreach, we were reaching communities previously underrepresented in our network.

We continue the work announced in our previous annual report to find the right long-term home for this crucially important network.

Future plans

As we move into the second year of our five-year strategy, our focus will be on building momentum and delivering even greater impact for the genetic, rare and undiagnosed community.

Our priorities for 2025–26

- Renewing the UK Rare Diseases Framework
  We will lead the call for a successor to the current Framework, ensuring that the priorities and commitments reflect the evolving needs of our community and build on lessons from the first phase.
- Driving newborn screening reform
  Launching our UK newborn screening policy report and campaign, backed by international best practice and co-produced recommendations.
- Improving diagnosis and care in the context of the 10 Year Health Plan for England
  Working with governments and NHS bodies to expand access to coordinated care, reduce diagnostic delays, and ensure equitable provision across all four nations.
- Strengthening patient voice and supporting research
  Expanding the Patient Empowerment Group, supporting member organisations to participate in policy processes, and embedding lived experience in research and service design.
- Consolidating the team
  Augmenting our Senior Management Team structure by bringing in a Director of Engagement and Impact to oversee a strategic approach to membership and communications.
- Being a better membership organisation
  Building a more varied approach to working with our diverse membership to ensure we are truly serving them all as best we can.
- Growing our reach and engagement
  Extending our public campaigns, education work, and community resources so that more people know about rare conditions and how to support those affected.

- Building sustainability
  Diversifying our funding streams and developing partnerships that enable us to maintain and grow our impact for years to come.
- Satisfying the needs of our stakeholders
  Doing what we do best by ensuring those that need the expertise of our community can access it as directly as possible in the most suitable way to inform their work.

With the dedication of our members, the commitment of our partners, and the energy of our team, we are ready to take the next steps towards a future where no one with a rare condition feels invisible or unsupported.

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.

> *'I think it's been an amazing day. It's been lovely to raise so much money, it's been lovely to spend the day with friends and have so much fun and it's been a lovely way to show our patients we are there for them in all manner of ways, not just in the clinic room.'* Participant in Ride for Rare

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 2024/25.

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 Therapeutics
BioCryst Pharmaceuticals
Biogen
Chiesi
Department of Health and Social Care
Inthallo)
Ipsen
Janssen
Jazz Pharmaceuticals

Johnson & Johnson
Kyowa Kirin
LifeArc
Medical Research Council
National Lottery Community Fund
National Institute of Health and Research
Novartis
Orchard Therapeutics
Pfizer
PTC Therapeutics
Rare Disease Research UK
Robert Luff Foundation
Roche
Sanofi
Scottish Government
Takeda
UCB
University College London
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 xx. The total income for the year was £885,853 (£780,935 in 2024).

This represents an overall increase of 13%, 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.

Expenditure

Total expenditure for the year was £705,016 (£862,752 in 2024).

This represents a 18% reduction 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 23% (36% in 2024), membership and engagement at 33% (37%), research at 32% (14%) and raising funds at 12% (13%), which means 88% (87%) of our spending is on charitable activities.

Surplus/deficit

Our final financial position for the year across all funds is a surplus of £180,837 (deficit of £81,817 in 2024).

This is comprised of a surplus of £160,593 on unrestricted funds and a surplus of £20,244 on restricted funds.

Reserves policy

Total reserves at the end of the financial year are £222,683 (£41,846 in 2024).

This is made up of restricted reserves of £32,378 (£12,134 in 2024) and unrestricted reserves of £190,305 (£29,712 in 2024).

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

Our unrestricted reserves represent more than six months of unrestricted expenditure and at the year end, and more than three months of unrestricted expenditure and restricted payroll. This meets the Trustees’ target 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

Genetic Alliance UK made big strides towards financial sustainability during 2024-25, which resulted in a solid financial performance. Adverse effects of continued challenges around fundraising were countered by careful planning and budgeting as well as an ongoing change management programme.

These circumstances resulted in unrestricted fund surplus compared to deficits for the previous two years. Unrestricted reserves (general and designated funds) stand at £190,305 as at 31 March 2025. The increase was as a result of the Trustees' implementation of a change management programme focused on income generation, cost savings and reductions in headcount in 2024-25. This focus on keeping costs under control will continue into 2025-26.

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, indicates that the charity will make a surplus in the year ending 31 March 2026 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.

Timothy Kamombo
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.

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 they are eligible for re-election for a further term of three years. After this they must retire unless they are elected to an officer post. 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.

Governance and organisational management

Trustees held five Board meetings in the year ending 31 March 2025, where they reviewed the charity's performance and determined and approved operating plans and budget.

During 2024/25 Trustees also held a Board Away Day to discuss leadership arrangements and 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 five times during 2024/25 and the People and Policies (P&P) committee which met three times during 2024/25.

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.

The P&P committee oversees 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.

Even in the context of reserve growth seen in 2024-25, the principal risk facing the organisation remains ‘failure to achieve financial plan due to failure in one or more income streams’. Existing mitigation includes monthly cashflow and management information, prompt collection of debts, and work to diversify income streams.

Fundraising
2024/25 saw a transition from undertaking most of our fundraising activities in-house, to selective use of a consultant for the purpose of grant applications. The majority of fundraised income continues to be secured by the work of Genetic Alliance UK staff. 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, Memorandum and Articles of Association, and constitutes a limited company, limited by guarantee, as defined in the Companies Act 2006.

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
Ms Gloria Clark (Chair of People and Policy Committee)
Ms Phillippa Farrant
Mr Toby Hannam
Miss Sara Hunt
Mr Timothy Kamombo (Treasurer and Chair of Finance and Governance Committee), co-opted January 2025

Board observer
Robin Nott

Chief Executive Officer
Nick Meade, Louise Fish, until July 2024, Mark Flannagan, between September 2024 and February 2025

Senior Management Team
Dr Amy Hunter, Nick Meade (as Director of Policy until February 2025, and as Interim Chief Executive from February 2025), Mary Edwards (until September 2024)

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

Management accountant
Fiona Bevan ACMA

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
X	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 25 September 2025 and signed on the Board’s behalf by:

Elizabeth Porterfield MBE
Chair of the 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 2025 set out on pages 32 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 2025, 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 pages 25 to 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:

- the nature of the industry and sector, control environment and business performance;
- results of our enquiries of management about their own identification and assessment of the risks of irregularities;
- any matters we identified having obtained and reviewed the Charity's documentation of their policies and procedures relating to;
- identifying, evaluating and complying with laws and regulations and whether they were aware of any instances of non-compliance;
- detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud;
- the internal controls established to mitigate risks of fraud or non-compliance with laws and regulations;

- the matters discussed among the audit engagement team regarding how and where fraud might occur;
- the financial statements and any potential indicators of fraud.

As a result of these procedures, we considered the opportunities and incentives that may exist within the organisation for fraud and identified the greatest potential for fraud in relation to timing of income recognition. In common with all audits under ISAs (UK), we are also required to perform specific procedures to respond to the risk of management override.

We also obtained an understanding of the legal and regulatory frameworks that the Charity operates in, focusing on provisions of those laws and regulations that had a direct effect on the determination of material amounts and disclosures in the financial statements. The key laws and regulations we considered in this context included the UK Charities Act.

In addition, we considered other laws and regulations that could have an effect on the charity and result in the imposition of financial or other penalties and litigation. Auditing standards limit the required audit procedures to identify non-compliance with these laws and regulations to enquiry of the directors and other management and inspection of regulatory and legal correspondence, if any. These limited procedures did not identify actual or suspected non-compliance.

All matters in relation to non-compliance with laws and regulations and potential fraud risks were communicated to all members of the engagement team and we remained alert to any indications of non-compliance throughout the audit.

Our procedures to respond to risks identified included the following:

- reviewing the financial statement disclosures and testing to supporting documentation to assess compliance with provisions of relevant laws and regulations described as having a direct effect on the financial statements;
- enquiring of management concerning actual and potential litigation and claims;
- assessing the appropriateness and where appropriate with third parties concerning actual and potential litigation and claims;
- performing analytical procedures to identify any unusual or unexpected relationships that may indicate risks of material misstatement due to fraud;
- in addressing the risk of fraud through management override of controls, reviewing the appropriateness of adjustments; assessing whether the judgements made in making accounting estimates are indicative of a potential bias; and evaluating the business rationale of any significant transactions that are unusual or outside the normal course of business.

We are not responsible for preventing non-compliance and cannot be expected to detect non-compliance with all laws and regulations.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

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 September 2025

STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME AND EXPENDITURE ACCOUNT)

YEAR ENDED 31 MARCH 2025

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £	Total Funds 2024 £
Income from:					
Donations and legacies	2	494,050	185,740	679,790	674,843
Charitable activities	3	47,108	158,071	205,179	105,953
Investments		884	-	884	139
Total income		542,042	343,811	885,853	780,935
Expenditure on:					
Raising funds	4	81,691	-	81,691	111,653
Charitable activities	5	299,757	323,567	623,324	751,099
Total expenditure		381,448	323,567	705,015	862,752
Net income/(expenditure)	8	160,594	20,244	180,838	(81,817)
Transfers between funds	18	-	-	-	-
Net movement in funds		160,594	20,244	180,838	(81,817)
Total funds at start of year	18	29,712	12,134	41,846	123,663
Total funds at end of year	18	190,306	32,378	222,684	41,846

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 2025

Charity number: 1114195
Company number: 05772999

	Note	**2025** **£**	2024 £
Fixed assets			
Tangible assets	**12**	2,911	5,634
		2,911	5,634
Current assets			
Debtors	**13**	16,843	101,901
Cash at bank and in hand		395,134	87,665
		411,977	189,566
Liabilities			
Creditors : amounts falling due within one year	**14**	(192,204)	(153,354)
Net current assets		219,773	36,212
Total assets less current liabilities		219,773	36,212
Net assets		222,684	41,846
FUNDS			
Unrestricted funds			
General funds	**19**	190,306	29,712
Designated funds	**19**	-	-
Restricted funds	**19**	32,378	12,134
Total funds		222,684	41,846

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 25 September 2025 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

CASH FLOW STATEMENT

YEAR ENDED 31 MARCH 2025

	Note	2025 £	2024 £
Net cash inflow/(outflow) from operating activiti	**15**	306,585	(52,632)
Non-operational cash flows:			
Investing activities			
Payments for tangible fixed assets		-	(3,381)
Investment income		884	139
Net cash inflow/(outflow) from investing activities		884	(3,242)
Net cash inflow/(outflow) for the year	**16**	307,469	(55,874)

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

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 Charities, in 2023/24 Genetic Alliance UK faced a challenging environment in with financial volatility and the cost of living crisis depressing charitable donations and placing inflationary pressure on costs. The timing of this challenge enabled the Charity to work throughout 2024-25 to mitigate the impact of these continuing economic challenges and saw some positive results of the change management programme instigated in 2023-24. Further measures confirmed in Q1 of 2024/25 allowed the Charity to build stability by further reducing the size of the team while growing its reserves.

The result of these changes meant unrestricted fund surplus for the year of £160K compared to a deficit for the previous year of c £63k. Unrestricted free reserves (general and designated funds less fixed assets) stand at approximately £187k as at 31 March 2025 compared to c £24k in the previous year.

The Trustees are mindful that the Charity continues 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 2026 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 included on a receivable basis.

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.

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.

1 Accounting policies *(continued)*

Cash
Cash balances represent cash and cash equivalents held with a maturity date of less than three months 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 2025 £
Donations from supporters	439,121	18,385	457,506
Legacies received	8,227	-	8,227
Robert Luff Trust	-	20,000	20,000
Wellcome Trust	-	5,000	5,000
Grants from Government			
National Lottery funding	-	97,078	97,078
Scottish Government	-	40,000	40,000
Other grants received	4,000	-	4,000
Donations through fundraising:			
Online donations	42,702	5,277	47,979
	494,050	185,740	679,790

2 Income from donations and legacies *(continued)*

Prior year

	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
Grants from Government			
National Lottery funding	-	67,693	67,693
Scottish Government	-	9,950	9,950
Other grants received	3,000	5,900	8,900
Donations through fundraising:			
Online donations	49,711	-	49,711
	452,198	222,645	674,843

3 Income from: Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £
Consultancy work	47,108	158,071	205,179
	47,108	158,071	205,179

Prior year

	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Consultancy work	55,885	50,068	105,953
	55,885	50,068	105,953

4 Expenditure on: Raising funds

		Total Funds 2025 £	Total Funds 2024 £
Staff costs, including consultancy work		74,673	106,009
Fees		3,816	2,083
Other direct costs		-	6
Support costs	(Note 6)	3,202	3,555
		81,691	111,653

During both the current and prior year, fundraising expenses have been incurred by unrestricted funds.

5 Expenditure on: Charitable activities

	Direct Costs £	Support Costs (Note 6) £	Total Funds 2025 £
Membership and Engagement	145,357	88,032	233,389
Policy work	111,211	52,025	163,236
Research	119,045	107,654	226,699
	375,613	247,711	623,324

Prior year	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
	398,049	353,050	751,099

£201,996 of the above support costs in notes 4 and 5 and £179,452 of direct costs relate to unrestricted funds spent during the year. £48,917 of support costs and £274,650 of direct costs relate to restricted funds spent during the year.
£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 prior year. £61,230 of support costs and £236,111 of direct costs relate 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 2025 £**
Staff costs		-	141,285	141,285
Communications		-	3,799	3,799
Office and admin costs		3,202	23,068	26,270
Travel		-	9,762	9,762
Finance costs		-	2,129	2,129
Professional fees		-	53,268	53,268
Governance costs	(Note 7)	-	14,400	14,400
		3,202	247,711	250,913

Prior year		**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
		3,555	353,050	356,605

7 Governance costs

	Total Funds 2025 £	Total Funds 2024 £
Auditor's fees - for audit services	11,400	10,800
Accounts review	3,000	3,240
	14,400	14,040

8 Net income/(expenditure) for the year

This is stated after charging:

	2025 £	2024 £
Auditor's remuneration - for audit services	11,400	10,800
Trustees travel and subsistence expenses (9 Trustees, 2024: 4 Trustees)	2,974	2,419
Depreciation	2,723	2,445

No Trustee received any remuneration in the current or prior year.

9 Staff costs and numbers

The aggregate payroll costs were:

	2025 £	2024 £
Wages & salaries	452,086	577,413
Social security costs	42,080	57,823
Pension contributions	25,067	33,371
Redundancy costs (2 employees)	4,064	3,635
	523,297	672,242

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

	2025	2024
Between £60,000 and £70,000	1	1

The average weekly number of employees during the year was 11 (2024: 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 £175,330 (2024: £236,405). 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.

11 Statement of Financial Activities comparative figures

For the year ended 31 March 2024	Unrestricted Funds £	Restricted Funds £	Total Funds 2024 £
Income from:			
Donations and legacies	452,198	222,645	674,843
Charitable activities	55,885	50,068	105,953
Investments	139	-	139
Total income	508,222	272,713	780,935
Expenditure on:			
Raising funds	111,653	-	111,653
Charitable activities	453,758	297,341	751,099
Total expenditure	565,411	297,341	862,752
Net income/(expenditure)	(57,189)	(24,628)	(81,817)
Transfers between funds	(6,073)	6,073	-
Net movement in funds	(63,262)	(18,555)	(81,817)
Total funds at start of year	92,974	30,689	123,663
Total funds at end of year	29,712	12,134	41,846

12 Tangible fixed assets

	Office equipment £	Total £
Cost or valuation		
At 1 April 2024	9,027	9,027
Additions	-	-
At 31 March 2025	9,027	9,027
Depreciation		
At 1 April 2024	3,393	3,393
Charge for the year	2,723	2,723
At 31 March 2025	6,116	6,116
Net book value		
At 31 March 2025	2,911	2,911
At 31 March 2024	5,634	5,634

13 Debtors

	2025 **£**	2024 £
Due in less than one year:		
Trade debtors	11,505	97,724
Prepayments and accrued income	5,338	3,517
Other debtors	-	660
	16,843	101,901

14 Creditors: amounts falling due within one year

	2025 **£**	2024 £
Trade creditors	11,597	4,700
Social security and other taxes	9,860	38,685
Other creditors	3,652	6,862
Accruals and deferred income	167,095	103,107
	192,204	153,354

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

	2025 **£**	2024 £
Statement of Financial Activities: Net movement in funds	180,838	(81,817)
Depreciation	2,723	2,445
Increase in creditors: current liabilities	38,850	75,412
Decrease / (increase) in debtors	85,058	(48,533)
Investment income	(884)	(139)
Net cash inflow/(outflow) from operating activities	306,585	(52,632)

16 Analysis of changes in cash during the year

	2025 **£**	2024 £	**Change** **£**
Cash at bank and in hand	395,134	87,665	307,469

	2024 **£**	2023 £	**Change** **£**
Cash at bank and in hand	87,665	141,457	(53,792)

17 Analysis of changes in net debt

	1 April 2024 £	Cashflow Movements £	31 March 2025 £
Cash at bank and in hand	87,665	307,469	395,134
	87,665	307,469	395,134

Prior year	1 April 2023 £	Cashflow Movements £	31 March 2024 £
Cash at bank and in hand	141,457	(53,792)	87,665
	141,457	(53,792)	87,665

18 Movement in Funds

For the year ended 31 March 2025

	At 1 April 2024 £	Income £	Expenditure £	Transfers £	At 31 March 2025 £
Restricted funds					
ARDAT	-	4,673	(4,673)	-	-
Concorde 2	-	25,694	(25,694)	-	-
DHSC	-	30,000	(30,000)	-	-
Generation evaluation	(91)	24,579	(24,488)	-	-
Captivate	(1,684)	18,315	(16,631)	-	-
How decisions are made in Scotland	-	20,000	(20,000)	-	-
LifeArc RD-TAPP	-	966	(966)	-	-
LifeArc working groups	-	16,931	(16,931)	-	-
Node Zhou	-	2,098	(2,098)	-	-
Node Billingham	-	6,496	(6,496)	-	-
SWAN UK National lottery	13,909	103,963	(85,494)	-	32,378
Wellcome 2023/25	-	5,000	(5,000)	-	-
Robert Luff Trust	-	8,656	(8,656)	-	-
NHS Scotland	-	11,177	(11,177)	-	-
Seeking a Rare Diagnosis	-	65,000	(65,000)	-	-
Rapid Genome Sequencing	-	263	(263)	-	-
	12,134	343,811	(323,567)	-	32,378
Unrestricted funds					
General funds	29,712	175,551	(205,683)	190,726	190,306
Designated funds					
Rare Disease Day	-	92,210	(92,210)	-	-
Rare Disease UK General Donations	-	274,281	(83,555)	(190,726)	-
	29,712	542,042	(381,448)	-	190,306
Total funds	41,846	885,853	(705,015)	-	222,684

Fund descriptions

Restricted funds

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

Concord 2- funds received for research on coordination of care in the UK and dissemination of findings.

Department of Health and Social Care (DHSC) - funds received to support and inform the rare disease team in the DHSC on the views of the rare disease community.

18 Movement in funds *(continued)*

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

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

How Decisions are Made in Scotland - funds received to explain healthcare decision-making on newborn screening, genetic services, access to medicines and service commissioning.

LifeArc RD-TAP - funds received to support the LifeArc Centre for Acceleration of Rare Disease Trials.

LifeArc working groups - funds received to support the policy, PPIE and comms working groups linked to the Centres.

Node Zhou - funds received to support RDRUK node research into UK Platform of Nucleic Acid Therapy (UPNAT).

Node Billingham - funds received to support RDRUK node research into Changing Clinical Practice Through Innovative Trial Design (CAPTIVATE).

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.

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).

Seeking a Rare Diagnosis - funds received to develop and launch a suite of information to support individuals and families seeking a diagnosis for a rare condition.

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.

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.

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.

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

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

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

SWAN UK Scotland - funds received for outreach in Scotland.

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.

18 Movement in funds *(continued)*

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.

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	-
	30,689	272,713	(297,341)	6,073	12,134
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)	-	-
	92,974	508,222	(565,411)	(6,073)	29,712
Total funds	123,663	780,935	(862,752)	-	41,846

19 Analysis of net assets between funds

As at 31 March 2025	Restricted Funds	Unrestricted Designated Funds	Unrestricted General Funds	Total
	£	£	£	£
Tangible fixed assets	-	-	2,911	2,911
Bank and cash	32,378	-	361,750	394,128
Other net assets	-	-	(174,355)	(174,355)
	32,378	-	190,306	222,684

As at 31 March 2024	Restricted Funds	Unrestricted Designated Funds	Unrestricted General Funds	Total
	£	£	£	£
Tangible fixed assets	-	-	5,634	5,634
Bank and cash	12,134	-	75,531	87,665
Other net assets	-	-	(51,453)	(51,453)
	12,134	-	29,712	41,846

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. No balances were due to or from related parties at the

Genetic Alliance UK – contactus@geneticalliance.org.uk – geneticalliance.org.uk
Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999