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GENETIC ALLIANCE UK ltd

Annual Report and Financial statements for the year ended 31 March 2026



Report of the Board of Trustees

For the year ended 31 March 2026

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2026.

The Trustees have adopted the provisions 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 photo: Tomoyuki Kono running the London Landmarks Half Marathon on behalf of Genetic Alliance UK – thanks Tomo!

Welcome from the Chair

This last year from April 2025 to March 2026 was the second year of our five-year strategy and the first year with Nick Meade as our Chief Executive. It has been an excellent year which saw Nick make great strides in his new role such that after a prolonged period of transition, the organisation has found solid ground – with strong and settled leadership through a strengthened and refocused senior team. This year also saw a welcome second consecutive surplus and reserves that now meet the Board's target. All of this progress and period of stability has translated directly into our success in enhancing our influence and reach.

The achievements of the year are set out in full in the pages that follow, however, a few stand out for me as worthy of specific mention:

- Securing the future of UK rare disease policy – we won a year's extension to the UK Rare Diseases Framework through direct engagement with all four health departments, and launched Future for Rare, our multi-stakeholder process to provide solid scientific/clinical evidence and, vitally, lived experience to shape its successor.
- Making the case for equity – our Rare Disease Day campaign, Equity for Rare, was shaped by 156 stakeholders and reached an estimated 10.7 million people, with Parliamentary receptions in Westminster, Holyrood and Cardiff Bay, and a UK-wide virtual event.
- Supporting undiagnosed families – SWAN UK held ten face-to-face meet-ups across England and launched three new animations, viewed more than 180,000 times; 88% of those who responded to our community survey told us SWAN UK had improved their access to support and information.
- Shaping research and screening policy – we published Time to Decide on newborn screening, progressed CONCORD2, completed our contribution to the independent evaluation of the Generation Study, and responded to 37 consultations on behalf of our members.

None of this happens without hard work and dedication. My heartfelt thanks and those of the whole Board go to our staff, whose commitment through several years of change has been remarkable; to my fellow Trustees for their support, scrutiny and generosity with their time and for sharing their expertise, knowledge and skills for our benefit; to the volunteers and community members who share their experiences so that others are better understood and recognised; and to our 250 member organisations, who are the reason the alliance carries weight. I am grateful, too, to our funders and partners, whose investment has extended our reach far beyond what we could achieve alone.

The 2026 AGM brings significant change to the Board. I step down as Trustee after nine years, six of them as Chair, as do four fellow trustees – Gloria Clark (immediate past Chair of the People & Policies (P&P) Committee), Sara Hunt, Sue Millman (immediate past Vice Chair), all of whom have also served nine years and Greg Stevenson who is standing down after three years. Each has given a great deal, and Sue's service as Vice Chair deserves particular thanks as does Gloria's role in setting up, nurturing and bringing the P&P Committee to the success it is now. We all leave knowing the Board is being renewed with Trustees of recognised standing and experience in our wide field of endeavour, whose appointment members will be asked to approve at the 2026 AGM.

At that AGM the appointment of my successor will be confirmed. I am delighted that Professor Timothy Barrett will succeed me as Chair. Tim is well known to the rare condition community,

brings the perspective of a clinical lead for specialised services and is active in research. He is also a well-recognised Board and Committee member in other charities and the NHS and will bring exactly the knowledge, skills, judgement and credibility the next phase of our continuing endeavours requires.

As this is my final letter as Chair, it is important also to look to the future. The next phase matters. The current UK Rare DiseasesFramework expires in January 2027. The Future for Rare summit this autumn set out what should follow, and our community's answer must be heard by all four UK Governments. Alongside that, we will decide the long-term home for SWAN UK, rebuild our digital infrastructure, and continue to build the financial resilience that makes ambition possible. Our future plans are set out later in this report.

It has been an honour and a privilege to be a Trustee and Chair of Genetic Alliance UK. I leave it stronger than I found it, in capable hands, and with plenty more to do alongside our members. Together we are turning rare experiences into lasting and meaningful 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 50% of childhood deaths are associated with a rare condition

Objective and Aims

Genetic Alliance UK (the 'charity') is an alliance of more than 250 charities, organisations and support groups. We have a thirty-five-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 2022 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 ambitions in the UK Rare Diseases Framework drive action across the UK. 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.

This is the second year of implementing our five-year Strategy for 2024 to 2029, launched at the charity's Annual General Meeting in Autumn 2023 following consultation with members, supporters and funders.

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.



Members of the Genetic Alliance UK team at the Westminster Rare Disease Day reception 2026

Highlights and Impact 2025–26

This year we have:

Influenced policy at the highest level

- Secured a year's extension to the UK Rare Diseases Framework, postponing its conclusion to January 2027, and launched 'Future for Rare', our multi-stakeholder process to shape its successor.
- Represented the rare condition community at the UK Rare Diseases Framework Board and in devolved implementation groups, and on more than 20 further national advisory boards and working groups.
- Published Time to Decide, our newborn screening policy report on international approaches to screening decision-making, shared with the UK National Screening Committee, the Chief Medical Officers of the UK and relevant ministers.
- Brought our community's perspectives to the design of the NHS 10 Year Health Plan for England.

Delivered high-profile campaigns

- Rare Disease Day 2026 – 'Equity for Rare', engaging 156 stakeholders in its development and reaching an estimated 10.7 million people through national and regional media.
- Hosted parliamentary receptions in Westminster, Holyrood and the Senedd, plus a UK-wide virtual event.
- Media coverage in the Guardian, Telegraph, Daily Record, Pharmaphorum and Daily Mail, and on ITV Wales, Ireland Live and Global Radio.

Strengthened patient voice

- Our Patient Empowerment Group (PEG) grew to more than 30 active members, contributing to the UK-wide Quality Standard for Rare Conditions and to securing the Framework extension.
- Identified and supported 15 individuals from diverse backgrounds to share their personal experience through vignettes, speeches and media.

Produced practical resources

- Published the Equity for Rare policy report, four accompanying factsheets, and a advocacy pack to help our community campaign for change on Rare Disease Day and beyond.

Advanced research and innovation

- Completed our contribution to the independent evaluation of the Generation Study, and progressed our CONCORD2 research on care coordination (funded by NIHR).
- Published joint research with Rare Disease Research UK and LifeArc on structural and cultural barriers to patient involvement in academic research, and co-authored two peer-reviewed articles. Ran our Early Career Researcher Award for a second year.

Engaged the public

- Launched three new SWAN UK animations, viewed more than 180,000 times on YouTube alone, and created three new films for healthcare professionals.
- Marked Undiagnosed Children's Day with events and media coverage across the country.

Built stronger partnerships

- Welcomed 19 new member organisations.
- Collaborated with a range of organisations, including LifeArc, the Neurological Alliance, Rare Disease Research UK, RareMinds, and the Specialised Healthcare Alliance on joint campaigns and advocacy.



Ashley Dalton MP, in her role as Parliamentary Under-Secretary of State for Public Health and Prevention, speaks at the Westminster Rare Disease Day reception, hosted by Peter Dowd MP, February 2026.

Voice of people living with rare conditions 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's membership has grown to more than 30, from just 12 before the pandemic, bringing together expert representatives from across the UK, including those holding formal patient voice roles in the implementation of the UK Rare Diseases Framework. The group met three times during the year and carried out significant work between meetings, focusing on translational research, the NHS 10 Year Plan, early detection, diagnosis, care coordination, newborn screening, data and registries, equitable access to medicines, and the overall care experience.

PEG contributed directly to the development of the UK-wide Quality Standard for Rare Conditions developed by NICE, and its ongoing work to identify progress and next steps for the Framework was pivotal in securing the year's extension.

Rare Disease Day: parliamentary receptions across all four nations

- Scottish Parliament – hosted by Bob Doris MSP, with over 50 attendees hearing from Emma and Ali Reed on living with Williams syndrome, and from Jenni Minto MSP, Minister for Public Health and Women's Health.
- Westminster – sponsored by Peter Dowd MP, with over 150 attendees, launching our Equity for Rare report and the NICE Quality Standard for Rare Diseases; Ashley Dalton MP, then Parliamentary Under-Secretary of State for Health and Social Care, launched the latest England Rare Disease Action Plan.
- Senedd/Cardiff – a drop-in session with Members including Jayne Bryant MS, Mike Hedges MS, Mark Isherwood MS, Russell George MS and Mabon ap Gwynfor MS, followed by a reception sponsored by John Griffiths MS at the Norwegian Church, Cardiff Bay.
- A joint four-nation webinar with over 100 registered attendees from health, policy, research and the rare condition community across all four nations.

'Thank you for the invitation to join the Rare Diseases Day event at the Parliament last week. It was great to meet some other people affected by rare diseases and to hear the commitment from Bob and Jenni to move things forward.'
Comment from attendee at Scottish Rare Disease Day Reception

Shaping National and Devolved Policy

With the extension to the UK Rare Diseases Framework secured, we recruited a steering group of people living with rare conditions, clinicians, researchers, research funders and industry bodies including the Bioindustry Association (BIA) and the Association of the British Pharmaceutical Industry (ABPI) to shape 'Future for Rare', our multi-stakeholder process to agree the priorities for a successor framework. The programme's call for evidence and UK-wide stakeholder survey were live as we ended the year, supported by a 'consultation in a box' model that enables organisations across all four nations, including those with limited capacity, to consult their own communities. A national summit is planned for autumn 2026 to agree a consolidated set of recommendations for all four governments.

- Continued our representation on the UK Rare Diseases Framework Board, the Rare Disease Implementation Network in Wales, and the Rare Disease Implementation Board in Scotland.
- Engaged with the NHS England/DHSC merger to ensure specialist services and genomics programmes are protected in any reformed system.
- Continued our collaboration with the Northern Ireland Rare Disease Partnership.
- Worked with the Department of Health and Social Care on the Down Syndrome Act, to ensure resulting guidance is fair to all people affected by genetic conditions.
- In an exceptional year for policy development, Genetic Alliance UK submitted responses to 37 consultations on behalf of our members. A further set of consultation opportunities were disseminated to the membership.
- In collaboration with LifeArc, published Accelerating R&D for Rare Disease in the UK and with the LifeArc Translational Centres for Rare Disease, published More Trials, Better Data, Faster Access.

International Collaboration

As members of EURORDIS, we continued to ensure UK perspectives shape global rare condition policy and practice, including through the Rare Disease International Mirror and Action Group and the international Priority Setting Partnership on rare conditions, to whose steering committee we were appointed this year.



Sara Hunt, Trustee; Ashley Dalton MP; Phillippa Farrant, past trustee; Nick Meade, Chief Executive; and Dr Shehla Mohammed, Trustee at the Westminster Rare Disease Day reception, February 2026.

Campaigns and Advocacy

Rare Disease Day 2026 – Equity for Rare

Rare Disease Day, on 28 February, is the highlight of our annual calendar, aligning with the international EURORDIS campaign to represent the nearly 300 million people living with a rare condition worldwide. Our 2026 campaign, 'Equity for Rare', made the case that understanding and dismantling the hidden inequities facing our community is a fundamental prerequisite for any effective rare conditions policy, not an optional extra.

We set out to engage at least 50 stakeholders in shaping the campaign; we engaged 156, through two member meetings, two workshops with people with lived experience, healthcare professionals and academics, including a workshop with Breaking Down Barriers' Experts by Experience group, and a survey on equity that received 243 responses. We identified and supported 15 individuals from diverse backgrounds to develop personal vignettes and take part in speaking and media opportunities, integrating their stories into our formal policy work and national and regional press coverage.

Our policy report, Equity for Rare: Delivering fairer healthcare systems for people affected by rare conditions, called on UK governments to deliver a UK-wide map of rare conditions through funded registries, close the evidence gap through fair research investment, mandate system-wide accountability, embed rare conditions in mainstream healthcare delivery, and commit to a bold successor to the UK Rare Diseases Framework. We developed four accompanying factsheets as a permanent legacy resource, and a free advocacy pack with template letters, media guidance, school toolkits and social media assets.

'Can I just say how great the new report is! I am so pleased to see the powerful focus on equity. Hopefully this will make budget holders think a bit differently about resource allocation.'
Member response to Rare Disease Day Report 2026

We secured coverage in the Guardian, Telegraph MediaPlanet supplement, Daily Record, Pharmaphorum and Daily Mail, plus ITV Wales evening news and Global Radio's regional stations across the Midlands, South East and East of England, for a combined estimated reach of over 10.7 million, achieved despite a very competitive news cycle. Across our own social media channels we achieved more than 184,850 views, up by as much as a third on 2025 on some platforms, with our Rare Disease Day page the most visited on our website in February and 466 downloads of our resources.

Working with Government on the Framework's future

Our year's central campaign has been securing the future of UK-wide rare disease policy. We secured a year's extension to the Framework in November 2025 through direct engagement with all four devolved health departments, building on the momentum of our Rare Disease Day 2025 report presented to delivery groups and implementation boards across the UK. Our proposal for a multi-stakeholder process to determine the Framework's successor was noted in both the Department of Health and Social Care's and the responsible Minister's announcement of the extension.

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.

CONCORD2 and Care Coordination

Coordination of care involves organising and sharing relevant information about a person's care between different services to avoid duplication and to achieve safer and more effective care – this is especially valuable to people living with rare conditions, but frequently omitted by healthcare providers. CONCORD2, the NIHR-funded programme assessing the costs and benefits of different models of care coordination, completed its literature review during the year and secured access to its first NHS study sites for data collection, with the project granted a three-month no-cost extension to July 2026.

Generation Study

We continued to support Genomics England's Generation Study, exploring the potential for genomic sequencing in newborns – which could allow for much wider implementation of pre-symptomatic detection of rare conditions, and completing data collection and analysis of patient organisation views for the official independent evaluation of the pilot, led by UCL. The analysis will address how prepared patient organisations are to support families taking part, and what impact genomic newborn screening will have on the families they support.

Improving patient involvement in research

With Rare Disease Research UK and LifeArc, we launched research and recommendations on the structural and cultural changes needed to improve patient involvement in academic research, leading to invitations to speak at the King's Health Partners Rare Disease Network and to contribute commentary to academic journals. We ran our Early Career Researcher Award in patient involvement in rare disease research for a second year continued to lead the policy workstream and support the patient and public involvement and communications workstreams for the LifeArc Translational Centres for Rare Disease.

Facilitating patient involvement

We facilitated patient and public involvement in a wide range of funded projects, including prenatal testing and therapies at Great Ormond Street Hospital, mechanisms of genetic disease at the Institute of Genetics and Cancer, University of Edinburgh, gene therapy research with the Accelerating Research and Development for Advance Therapies (ARDAT) Consortium, genomic newborn screening research at the University of Warwick, and views on the 14-day embryo research limit with National Voices, Ipsos and the Nuffield Council on Bioethics. We also delivered 46 statements on rare conditions across the year to support the HFEA's PGT licensing process.

International Engagement

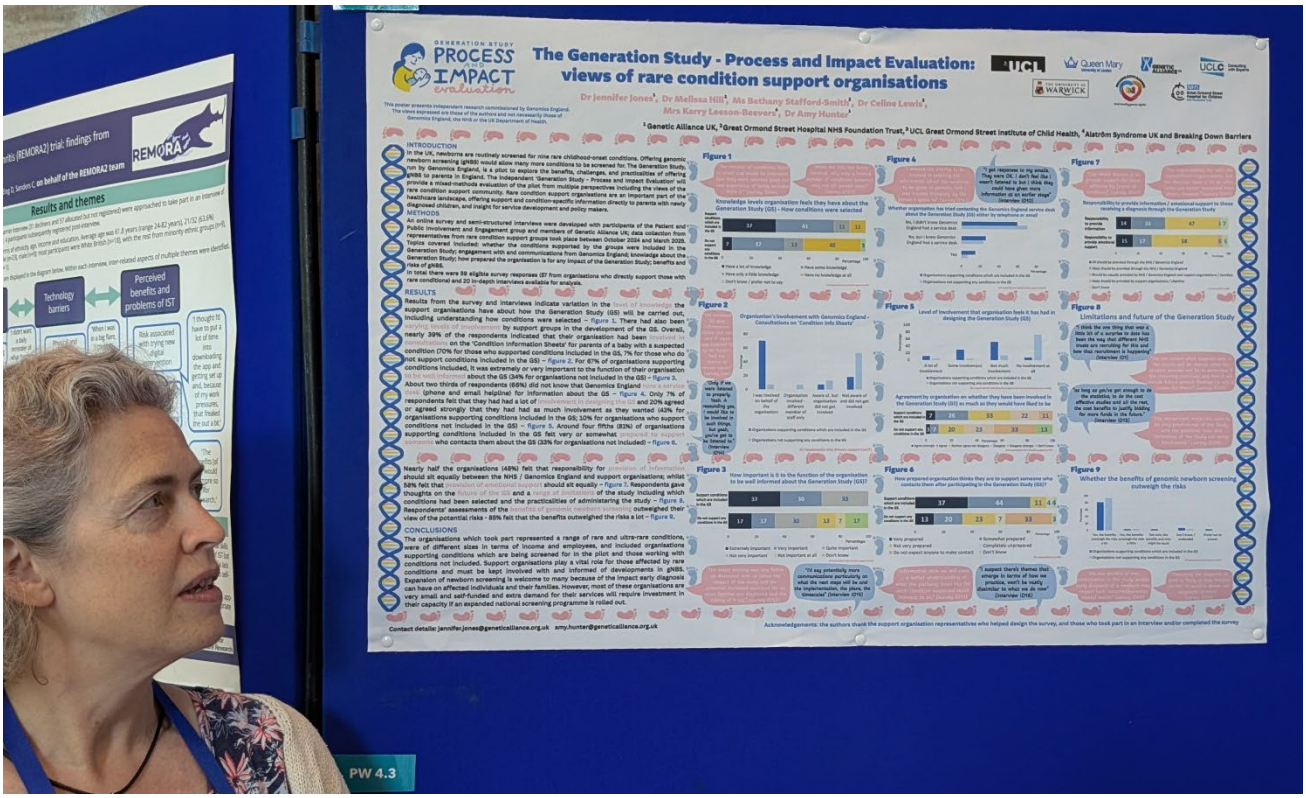
Our involvement in international forums, including the Rare Disease International Mirror and Action Group and the international Priority Setting Partnership on rare conditions, ensured UK patient perspectives continued to shape global discussions on rare condition research and policy.

Adding to the evidence base

Partnerships with a range of academic teams generated two publications in peer-reviewed scientific journals, focussed on quality-of-life measures in rare genetic conditions[1], and the patient-driven Rare Disease Research Network[2].

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 2025–26 has built further on the foundations laid last year, positioning us to deliver research that advances science while meeting the real needs of our community.



Dr Jennifer Jones presenting work to evaluate The Generation Study.

[1] Bourke M, Zhu X, Boughtwood T, Gaff C, Hunter A, Mulhern B, Peasgood T, Stuart C, Buchanan J, Goranitis I. Content validity, face validity and comprehensiveness of generic quality-of-life measures in adults and children with rare genetic conditions and their carers: a think aloud qualitative study. Qual Life Res. 2026 Jun 28;35(8):221. doi: 10.1007/s11136-026-04324-7. PMID: 42365553; PMCID: PMC13310824.

[2] 2: Balfour J, Cowley LB, Windsor G, Dalby E, Sibley M, Hunter A, Smith RM. The patient-driven Rare Disease Research Network: turning research on its head. BMJ Open. 2025 Oct 27;15(10):e105045. doi: 10.1136/bmjopen-2025-105045. PMID: 41145264; PMCID: PMC12570899.

Membership and Partnerships

Our members are at the heart of everything we do. In 2025–26 we worked with more than 240 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. We work to ensure that all of our members, regardless of size or resource, have a voice and share our platform.

Supporting and Connecting Members

- Monthly Member Meetings, typically attracting 40 or more attendees, covering topics from the Clinical Genomics Transformation Programme to the UK Rare Diseases Framework extension, the MHRA's regulatory announcement and the Down Syndrome Act.
- We welcomed 19 new member organisations across the year: Bruck Syndrome Charity, CHAMP1 UK, Childhood Tumour Trust, CURE GABA-A, Fahr Beyond, Genetic Overgrowth PI3K Support, Harry's HAT, Heart UK, HFI UK, Krabbe UK, Lynch Syndrome UK, Pathfinders Neuromuscular Alliance, Pregnancy Associated Osteoporosis UK, Rare People (The Research Charity), SUDC UK, The Mikaere Foundation and Usher Kids UK.
- Monthly Member News emails kept the community informed of consultations, funding opportunities, research studies and events, with open rates consistently high (above 50%).
- Campaign toolkits equipping members with materials for Rare Disease Day, including social media assets, exhibition resources and template press releases.
- Advocacy packs for individuals living with rare conditions with guidance and templates to drive change on Rare Disease Day and beyond.

Collaborating for Change

- Partnered with Neurological Alliance, Specialised Healthcare Alliance, Rare Disease Research UK and LifeArc on joint campaigns, events and advocacy.
- Worked with the Charity Medicines Access Coalition to improve equity in treatment availability.
- Signed an agreement with the Association of Genetic Nurses and Counsellors endorsing their decision to prioritise partnership with people living with genetic, rare and undiagnosed conditions.

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.









Clockwise from top: Liz Twist MP hosting the LifeArc Translational Centres for Rare Disease (TCRD) parliamentary drop in, organised by Genetic Alliance UK on behalf of the TCRD hub; Nick Meade, Chief Executive and Roberta Rizzo, Chair of the Association of Genetic Nurses and Counsellors; Naomi Webborn from TOFS UK; Rhiannon Edwards, NHS Wales and Sophie Mira Roberts, Breaking Down Barriers at the Wales Rare Disease Day reception.

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 2025–26, our work focused on deepening community connections, expanding our reach, and developing new resources for families and professionals.

Strengthening community connections

We reconnected with long-standing families and welcomed new ones through ten face-to-face meet-ups across England, including Yorkshire and the Humber, the North West, the West Midlands, the South West, the South East and the East Midlands, alongside a growing programme of virtual coffee meet-ups and events such as our 'sing and sign' sessions.

'There are so few places that make us feel welcome. We also met some lovely families who know how difficult life can be so it was really nice to feel understood.' – SWAN UK community member

Sharing information and building confidence

Working with Contact, we delivered virtual information events shaped by what the community told us would be most helpful; 100% of attendees at our workshop on supporting parents of children with anxiety said they felt less isolated afterwards.

Developing professional resources

We completed and launched three new animations: What is a genetic condition?, How are genetic conditions diagnosed?, and Why do some genetic conditions remain undiagnosed?, viewed more than 180,000 times combined and shared by partners including Genomics England, Unique, Contact and the Institute of Health Visiting. We also produced three new films for healthcare professionals, featuring a consultant clinical geneticist, the SWAN nurse at Great Ormond Street Hospital, and a SWAN UK family, launched around Undiagnosed Children's Day.

Working with RareMinds, we delivered separate wellbeing workshops for mums and dads and launched a new leaflet, Parenting a child with an undiagnosed genetic condition: you and your emotional wellbeing, as a permanent resource for families.

Expanding our reach

Our main Facebook group saw over 600 posts and more than 4,700 comments across the year, and our public Facebook page had over 550,000 views. In our community survey, 88% of respondents said SWAN UK had improved their access to support and information, and over 80% said they felt less isolated as a result of being part of the community.

We continue the work announced in our previous annual report to find the right long-term home for this crucially important network. Following a thorough review process, involving a dedicated Task and Finish Group with representation from SWAN UK families and our trustees, we have reached a decision on the direction for SWAN UK's future. In 2026–27 we will begin exploring the transfer of the SWAN UK support programme to a partner organisation best placed to help it thrive for years to come, engaging the community fully as this work progresses.

Future plans

As we move into the third year of our five-year strategy, our focus turns to the single most important task facing the organisation: securing a successor to the UK Rare Diseases Framework ahead of its expiry in January 2027.

Our priorities for 2026–27

- **Delivering Future for Rare –** leading the Future for Rare multi-stakeholder process through to its national consensus summit in autumn 2026, producing a final report for governments across all four nations.
- **Continuing our policy and public affairs programme –** on newborn and population screening, medicines access, NHS reform and undiagnosed conditions, alongside coordinated parliamentary engagement across all four nations, including a community campaign around the devolved elections.
- **Being a better membership organisation –** completing a thorough review of our membership offer and fee structure.
- **Progressing our funded research programmes –** including CONCORD2, the Rare Disease Research UK Platform, and our LifeArc Centres partnership.
- **Rebuilding our digital infrastructure –** delivering a new website with improved member resources, policy content, accessibility and fundraising capability.
- **Deciding the future of SWAN UK –** beginning formal discussions on transferring the SWAN UK support programme to a partner organisation, while continuing to deliver for the community.
- **Building sustainability –** recruiting to our new fundraising post and developing a fuller fundraising strategy for Board approval.
- **Strengthening our governance –** continuing trustee recruitment and development of our risk register.

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 genetic, rare or undiagnosed 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.

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 Pharmaceuticals
Amgen
Amicus Therapeutics
BioCryst / Neopharmed Gentili
Biogen
Chiesi
D'Oyly Carte Charitable Trust
Illumina
Inthallo
Ipsen
Jazz Pharmaceuticals
Johnson & Johnson
Kyowa Kirin
LifeArc
National Lottery Community Fund
Novartis Pharmaceuticals
Orchard Therapeutics
Pharming
PTC Therapeutics
Rare Disease Research UK
Robert Luff Foundation
Sanofi
Scottish Government
Takeda
UCB
Ultragenyx Pharmaceutical
Vertex Pharmaceuticals
Wellcome Trust

Treasurer’s letter and financial review

Thank you to all our members, supporters and funders. Your support has enabled the important impact that Genetic Alliance’s work has delivered over the last year. Without you, the achievements and progress outlined in this report would not be possible.

Review of the financial position

The results for the year are set out in the statement of financial activities on page 30.

Income

Total income for the year was £854,745 (£885,853 in 2025).

This represents an overall decrease of 3.5%, which was due to the mix of income sources compared to 2025. 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 £732,805 (£705,015 in 2025).

This represents a 4% increase on the prior year and reflects a continued focus on cost control. Changes in team sizes saw a shift in categorisation of spending from membership engagement to policy work with our members over the period with policy work at 36% (23% in 2025), membership and engagement at 20% (33%), research at 35% (32%) and raising funds at 10% (12%), which means 90% (88%) of our spending is on charitable activities.

Surplus/deficit

Our final financial position for the year across all funds is a surplus of £121,940 (surplus of £180,838 in 2025).

This is comprised of a surplus of £124,439 on unrestricted funds and a deficit of £2499 on restricted funds.

Reserves policy

Total reserves at the end of the financial year are £344,624 (£222,684 in 2025).

This is made up of restricted reserves of £30,541 (£32, 378 in 2025), designated Funds £96,667 (£0 in 2025) and unrestricted reserves of £217,416 (£190,306 in 2025).

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

Our unrestricted and designated reserves represent more than six months of unrestricted expenditure. 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 continued to make big strides towards financial sustainability during 2025-26, 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 a second year of unrestricted fund surplus following a surplus in the previous year. Unrestricted reserves (general and designated funds) stand at £314,083 as at 31 March 2026. The increase was as a result of the Trustees' continued implementation of a change management programme focused on income generation, cost savings and reductions in headcount over 2025-26. This focus on keeping costs under control will continue into 2026-27.

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 a period of at least 12 months from the date of approval of these financial statements on that basis.

This work, informed by prudent assumptions and focused on ensuring financial sustainability, indicates that the Charity is expected to make a surplus in the year ending 31 March 2027 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. Trustees serve a three-year term and may be re-elected once. They must then retire, unless elected to an officer post (which may be held for up to six years, followed by a final three-year term as a trustee) or unless special circumstances justify one further three-year term. Retiring trustees may not return to the Board for twelve months. 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 four Board meetings in the year ending 31 March 2026, where they reviewed the charity’s performance and determined and approved operating plans and budget. During 2025/26 Trustees also held a Board Away Day to discuss the digital strategy, the organisation’s values, and succession planning for the Board. Trustees approved the Annual Report and passed all motions at the charity's Annual General Meeting in October 2025.

Trustees delegate certain powers in connection with the charity's management, remuneration and administration to the Finance and Governance (F&G) committee (which met four times) and the People and Policies (P&P) committee (which met three times). The F&G committee provides detailed oversight and advice to the Board in relation to financial management, financial viability, risk management and governance, and has a minimum of three Trustee members including the Treasurer (Chair of the Committee), the Chair of Genetic Alliance UK, and the Vice Chair. The Chief Executive and Directors are ex officio members. 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 at each Board meeting have discussed methods to manage those risks, reviewed at each Board and F&G committee meeting. Work continued during the year to complete development of the risk register and implement a regular cycle of review.

The principal risk facing the organisation remains 'failure to achieve financial plan due to failure in one or more income streams', however this has been down-graded following the second year of planned surplus. Existing mitigation includes monthly cashflow and management information, prompt collection of debts, and work to diversify income streams.

Fundraising

During the year we appointed a fundraising consultant to develop our case for support and pursue trust and foundation income. 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.

The charity used a consultant professional fundraiser for portions of this year, supporting preparation of our applications to trusts and foundations. Our fundraising work is overseen by the Chief Executive and reported to the F&G committee. We are committed to protecting vulnerable people and other members of the public from unreasonably intrusive or persistent fundraising approaches or undue pressure to give.

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 1UR

Postal address

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

Trustees

Ms Lara Bloom

Ms Gloria Clark (Chair of People and Policy Committee until September 2026, stepping down as trustee at the 2026 AGM)

Mr Toby Hannam (Chair of People and Policy Committee since September 2026)

Miss Sara Hunt (stepping down as trustee at the 2026 AGM)

Mr Timothy Kamombo (Treasurer and Chair of Finance and Governance Committee)

Ms Emily Merrell

Mrs Sue Millman (Vice Chair until 11 March 2026, stepping down as trustee at the 2026 AGM)

Ms Rebecca Middleton

Dr Shehla Mohammed

Mrs Elizabeth Porterfield MBE (Chair, stepping down as trustee at the 2026 AGM)

Mr Greg Stevenson (stepping down as trustee at the 2026 AGM)

Dr Mike Winter (Vice Chair since 11 March 2026)

Dr Timothy Barrett, a paediatrician working in rare condition care and research, will take up the role of Chair subject to approval at the 2026 AGM.

Board observer

Robin Nott

Chief Executive

Nick Meade

Senior Management Team

Dr Amy Hunter (Director of Research), Natalie Frankish (Director of Public Affairs from December 2025), Dr Anna Couturier (Director of Engagement and Impact from January 2026)

Auditors

Nyman Libson Paul LLP, 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

Website	geneticalliance.org.uk
Facebook	GeneticAllianceUK
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 Board will propose to the members at the 2026 AGM that two decisions on future audit will be delegated to the Treasurer:

- whether to conduct an audit or an independent examination of the accounts
- the appointment of the auditors

Report of the Trustees, incorporating a strategic report, approved by order of the Board of Trustees, as the company directors, 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 2026 set out on pages 30 to 47 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 2026, 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 25 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 in 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
Signer ID: AO71REFVVR...

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: 06/10/2026 PDT

GENETIC ALLIANCE UK LTD

STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME AND EXPENDITURE ACCOUNT)

YEAR ENDED 31 MARCH 2026

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2026 £	Total Funds 2025 £
Income from:					
Donations and legacies	**2**	369,842	232,820	602,662	679,790
Charitable activities	**3**	47,920	202,185	250,105	205,179
Investments		1,978	-	1,978	884
Total income		419,740	435,005	854,745	885,853
Expenditure on:					
Raising funds	**4**	72,508	-	72,508	81,691
Charitable activities	**5**	222,793	437,504	660,297	623,324
Total expenditure		295,301	437,504	732,805	705,015
Net income/(expenditure)	**8**	124,439	(2,499)	121,940	180,838
Transfers between funds	**19**	(662)	662	-	-
Net movement in funds		123,777	(1,837)	121,940	180,838
Total funds at start of year	**19**	190,306	32,378	222,684	41,846
Total funds at end of year	**19**	314,083	30,541	344,624	222,684

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 33 to 47 form part of these financial statements
See note 11 for fund-accounting comparative figures

GENETIC ALLIANCE UK LTD

BALANCE SHEET

Charity number: 1114195

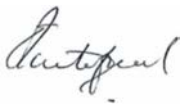
AS AT 31 MARCH 2026

Company number: 05772999

	Note	2026 £	2025 £
Fixed assets			
Tangible assets	**12**	1,059	2,911
		1,059	2,911
Current assets			
Debtors	**13**	63,202	16,843
Cash at bank and in hand		607,241	395,134
		670,443	411,977
Liabilities			
Creditors : amounts falling due within one year	**14**	(326,878)	(192,204)
Net current assets		343,565	219,773
Total assets less current liabilities		344,624	222,684
Net assets		344,624	222,684
FUNDS			
Unrestricted funds			
General funds	**20**	217,416	190,306
Designated funds	**20**	96,667	-
Restricted funds	**20**	30,541	32,378
Total funds		344,624	222,684

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 30 September and are signed on their behalf by:



Elizabeth Porterfield, MBE
Chair of Trustees

The notes on pages 33 to 47 form part of these financial statements

GENETIC ALLIANCE UK LTD

CASH FLOW STATEMENT

YEAR ENDED 31 MARCH 2026

	Note	2026 £	2025 £
Net cash inflow/(outflow) from operating activities	**16**	210,639	306,585
Non-operational cash flows:			
Investing activities			
Payments for tangible fixed assets		(510)	-
Investment income		1,978	884
Net cash inflow/(outflow) from investing activities		1,468	884
Net cash inflow/(outflow) for the year	**17**	212,107	307,469

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 33 to 47 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 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

The financial statements have been prepared on the going concern basis.

The charity recorded net income for the year of £121,940 (2025: £180,838), comprising an unrestricted surplus of £124,439 (2025: £160,594) and a small net deficit on restricted funds of £2,499 (2025: surplus £20,244). Total funds carried forward at 31 March 2026 were £344,624 (2025: £222,684), made up of unrestricted funds of £314,083 (2025: £190,306) of which £96,667 (2025: £nil) was designated by the trustees for specific purposes and restricted funds of £30,541 (2025: £32,378).

The trustees have reviewed the charity's budgets and cash flow forecasts covering a period of at least twelve months from the date of approval of these financial statements. The forecast reflects contracted and committed grant income, the anticipated income pipeline across the charity's core activities and its Rare Disease UK and SWAN UK projects, together with budgeted expenditure on staff, programmes and support costs. Sensitivity has been applied to key income streams, and the trustees are satisfied that the charity would remain able to meet its liabilities as and when they fall due.

Having considered the charity's current financial position, the level of free reserves available, and the outcome of the forecast review, the trustees have concluded that there are no material uncertainties relating to events or conditions that cast significant doubt on the charity's ability to continue as a going concern. Accordingly, the Trustees consider it appropriate to continue to adopt the going concern basis in preparing the 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 19 to the financial statements.

2 Income from donations and legacies

	Unrestricted Funds	Restricted Funds	Total Funds 2026
	£	£	£
Donations from supporters	336,244	31,439	367,683
Legacies received	220	-	220
Wellcome Trust	-	15,000	15,000
The D'Oyly Carte	12,000	-	12,000
Grants from Government			
National Lottery funding	-	80,277	80,277
Scottish Government	-	54,111	54,111
Department of Health and Social Care	-	50,000	50,000
Donations through fundraising:			
Online donations	21,378	1,993	23,371
	369,842	232,820	602,662

2 Income from donations and legacies *(continued)*

Prior year

	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
Great Ormond Street Hospital	-	-	-
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

3 Income from: Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2026 £
Consultancy work	47,920	202,185	250,105
	47,920	202,185	250,105

Prior year

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

4 Expenditure on: Raising funds

		Total Funds 2026 £	Total Funds 2025 £
Staff costs, including consultancy work		65,175	74,673
Fees		1,340	3,816
Support costs	(Note 6)	5,993	3,202
		72,508	81,691

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 2026 £
Membership and Engagement	107,379	38,230	145,609
Policy work	205,787	56,031	261,818
Research	175,258	77,612	252,870
	488,424	171,873	660,297

Prior year	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

£109,758 of the above support costs in notes 4 and 5 and £185,543 of direct costs relate to unrestricted funds spent during the year. £68,108 of support costs and £369,396 of direct costs relate to restricted funds spent during the year.
£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 prior year. £48,917 of support costs and £274,650 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 2026 £
Staff costs		-	39,123	39,123
Communications		-	4,627	4,627
Office and admin costs		5,993	50,005	55,998
Travel		-	10,171	10,171
Finance costs		-	120	120
Professional fees		-	51,993	51,993
Governance costs	(Note 7)	-	15,834	15,834
		5,993	171,873	177,866

Prior year		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

7 Governance costs

	Total Funds 2026 £	Total Funds 2025 £
Auditor's fees - for audit services	12,000	11,400
Accounts review	3,834	3,000
	15,834	14,400

8 Net income/(expenditure) for the year

This is stated after charging:

	2026 £	2025 £
Auditor's remuneration - for audit services	12,000	11,400
Trustees travel and subsistence expenses (4 Trustees, 2025: 9 Trustees)	1,377	2,974
Depreciation	2,362	2,723

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

9 Staff costs and numbers

The aggregate payroll costs were:

	2026 £	2025 £
Wages & salaries	403,671	452,086
Social security costs	42,670	42,080
Pension contributions	27,915	25,067
Redundancy costs (2 employees)	-	4,064
	474,256	523,297

The number of employees whose employment benefits (excluding employer's national insurance and pension contributions) exceeded £60,000 during the year were:

	2026	2025
Between £60,000 and £70,000	-	1
Between £70,001 and £80,000	1	-

The average weekly number of employees during the year was 10 (2025: 11), 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 £191,615 (2025: £175,330). 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 2025	Unrestricted Funds £	Restricted Funds £	Total Funds 2025 £
Income from:			
Donations and legacies	494,050	185,740	679,790
Charitable activities	47,108	158,071	205,179
Investments	884	-	884
Total income	542,042	343,811	885,853
Expenditure on:			
Raising funds	81,691	-	81,691
Charitable activities	299,757	323,567	623,324
Total expenditure	381,448	323,567	705,015
Net income/(expenditure)	160,594	20,244	180,838
Transfers between funds	-	-	-
Net movement in funds	160,594	20,244	180,838
Total funds at start of year	29,712	12,134	41,846
Total funds at end of year	190,306	32,378	222,684

12 Tangible fixed assets

	Office equipment £	Total £
Cost or valuation		
At 1 April 2025	9,027	9,027
Additions	510	510
At 31 March 2026	9,537	9,537
Depreciation		
At 1 April 2025	6,116	6,116
Charge for the year	2,362	2,362
At 31 March 2026	8,478	8,478
Net book value		
At 31 March 2026	1,059	1,059
At 31 March 2025	2,911	2,911

13 Debtors

	2026 £	2025 £
Due in less than one year:		
Trade debtors	60,377	11,505
Prepayments and accrued income	2,825	5,338
	63,202	16,843

14 Creditors: amounts falling due within one year

	2026 £	2025 £
Trade creditors	49,161	11,597
Social security and other taxes	14,529	9,860
Other creditors	7,757	3,652
Accruals	15,553	18,189
Deferred income (see note 15)	239,878	148,906
	326,878	192,204

15 Deferred income

	2026 £	2025 £
Balance at start of year	148,906	84,624
Income released during the year	(148,906)	(84,624)
Income deferred in the year	239,878	148,906
Balance at end of the year	239,878	148,906

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

	2026 £	2025 £
Statement of Financial Activities: Net movement in funds	121,940	180,838
Depreciation	2,362	2,723
Increase in creditors: current liabilities	134,674	38,850
Decrease / (increase) in debtors	(46,359)	85,058
Investment income	(1,978)	(884)
Net cash inflow/(outflow) from operating activities	210,639	306,585

17 Analysis of changes in cash during the year

	2026 £	2025 £	Change £
Cash at bank and in hand	607,241	395,134	212,107

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

18 Analysis of changes in net debt

	1 April 2025 £	Cashflow Movements £	31 March 2026 £
Cash at bank and in hand	395,134	212,107	607,241
	395,134	212,107	607,241

Prior year	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

19 Movement in Funds

For the year ended 31 March 2026

	At 1 April 2025 £	Income £	Expenditure £	Transfers £	At 31 March 2026 £
Restricted funds					
ARDAT	-	3,927	(3,927)	-	-
Concorde 2	-	34,363	(34,363)	-	-
The D-Oyly Carte Trust	-	-	-	-	-
DHSC	-	50,000	(50,000)	-	-
ERDERA	-	-	(662)	662	-
Generation Evaluation	-	20,083	(20,083)	-	-
LifeArc Centre ARDT	-	9,443	(9,443)	-	-
LifeArc working groups	-	101,592	(101,592)	-	-
Node Zhou	-	705	(705)	-	-
Node Billingham	-	2,317	(2,317)	-	-
Pre-natal therapies - Lift Off		19,385	(19,385)	-	-
Rare Care	-	840	(840)	-	-
RD Research Hub	-	18,049	(18,049)	-	-
Robert Luff Trust	-	11,344	(11,344)	-	-
Scotland Boost	-	54,111	(45,002)	-	9,109
SWAN UK National Lottery	32,378	92,357	(103,303)	-	21,432
SWAN UK Wales	-	1,489	(1,489)	-	-
Wellcome 23-25	-	15,000	(15,000)	-	-
	32,378	435,005	(437,504)	662	30,541
Unrestricted funds					
General funds	190,306	181,070	(153,298)	(662)	217,416
Designated funds					
Matched Funding	-	20,000	(20,000)	-	-
Rare Disease Day	-	78,163	(78,163)	-	-
Rare Disease UK General Donations	-	140,507	(43,840)		96,667
	190,306	419,740	(295,301)	(662)	314,083
Total funds	222,684	854,745	(732,805)	-	344,624

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.

The D-Oyly Carte Trust - funds received to provide activities to support people diagnosed with inherited conditions**.**

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.

19 Movement in funds *(continued)*

ERDERA - funds received to support research pogrammes for people living with rare conditions**.**

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

LifeArc ARDT - 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).

Pre-natal therapies - Lift Off grant - funds to support research into pre-natal therapies**.**

Rare Care - funds received to enable a parent voice for evaluating the UK Rare Diseases Framework**.**

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.

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

Scotland Boost - funds received support the implementation of the UK Rare Diseases Framework in Scotland.

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

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

Wellcome 2023-25 - funding received from the Wellcome Trust for strategy development, implementation of a quality and diversity review and fundraising support.

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.

SWAN UK National Lottery Fund A - funds received to support families with children with undiagnosed conditions.

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.

Designated funds

Rare Disease Day - funds were set aside by the trustees in previous years to support awareness of rare conditions.

19 Movement in funds *(continued)*

Designated 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.

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

20 Analysis of net assets between funds

As at 31 March 2026	Restricted Funds	Unrestricted Designated Funds	Unrestricted General Funds	Total
	£	£	£	£
Tangible fixed assets	-	-	1,059	1,059
Bank and cash	30,541	96,667	480,033	607,241
Other net assets	-	-	(263,676)	(263,676)
	30,541	96,667	217,416	344,624

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	-	362,756	395,134
Other net assets	-	-	(175,361)	(175,361)
	32,378	-	190,306	222,684

21 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 year end.