

# GENETIC ALLIANCE UK LTD

England & Wales · Charity number 1114195

## Details

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Other names	GENETIC INTEREST GROUP, GENETIC INTEREST GROUP LIMITED, RARE DISEASE UK, RDUK, SWAN UK
Status	Registered
Legal form	Charitable company
Company number	<a href="#">05772999</a>
Registered	2006-05-15
Register	<a href="#">View on the Charity Commission register</a>

## Contact

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Website	<a href="http://www.geneticalliance.org.uk">www.geneticalliance.org.uk</a>

## Activities

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**Objects:** THE OBJECTS FOR THE PUBLIC BENEFIT ARE:-A) TO RELIEVE PERSONS AFFECTED BY A GENETIC CONDITIONS;B) TO ADVANCE THE EDUCATION OF THE PUBLIC CONCERNING GENETIC CONDITIONS IN SUCH WAYS AS THE TRUSTEES OF THE CHARITY THINK FIT.

**Activities:** Genetic Alliance UK is an alliance of over 230 charities and support groups. We have a 30-year track record of working together to improve the lives of people in the UK with lifelong and complex genetic and rare conditions. We run two long-standing projects, Rare Disease UK and SWAN UK.

## Classification

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- **How:** Provides Advocacy/advice/information, Acts As An Umbrella Or Resource Body
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups, The General Public/mankind

## Geography

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- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2025-03-31	£885,853	£705,015	£222,684	11
2024-03-31	£780,935	£862,752	£41,846	17
2023-03-31	£741,859	£769,204	£123,663	16
2022-03-31	£713,568	£762,424	£151,008	17
2021-03-31	£939,440	£808,907	£199,864	17

## Trustees

Name	Role	Appointed
<b>Elizabeth Porterfield</b>	Chair	2017-09-26
Dr Michael Winter FRCGP		2025-02-11
Dr Shehla Nilofer Mohammed		2023-09-12
Emily Merrell		2025-11-04
GLORIA JANE CLARK		2017-09-26
Gregor Stevenson		2023-09-12
Professor Lara Bloom		2023-09-12
Rebecca Middleton		2025-02-11
SARA JOHANNE HUNT		2017-09-26
Susan Jane Millman		2017-09-26
Timothy Kamombo		2025-01-20
Toby William Hannam		2023-09-12

**GENETIC ALLIANCE UK LTD**

England & Wales - Charity number 1114195

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# Accounts

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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](mailto:contactus@geneticalliance.org.uk) – [geneticalliance.org.uk](http://geneticalliance.org.uk)

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

## 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.

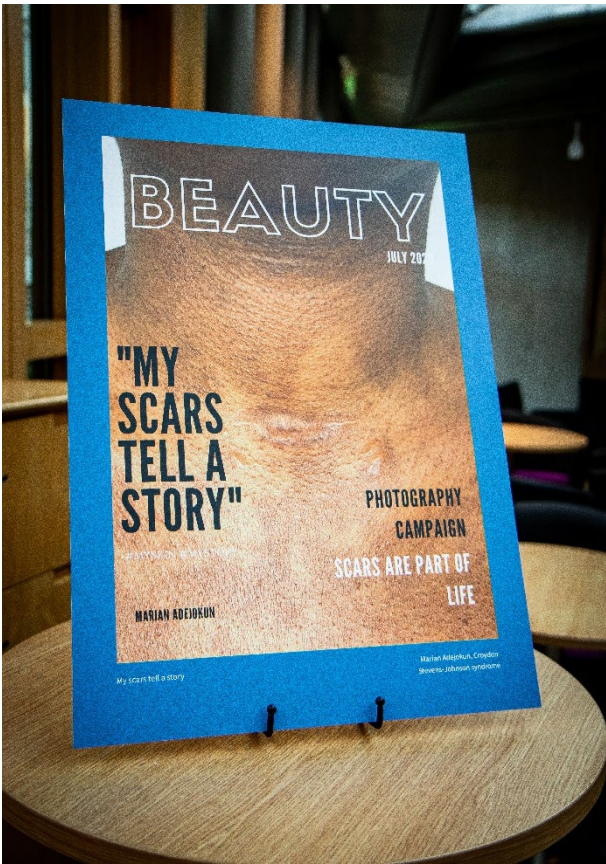
- Anthology and Policy Report – Over 60 creative submissions from people aged 9 to 71, representing more than 50 conditions, were brought together in an anthology. Alongside it, we launched a policy report calling for a renewed UK Rare Diseases Framework.
- Parliamentary Receptions – Hosted events in 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.'* –  
theyasthenicmedic, 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.

A handwritten signature in black ink, consisting of several overlapping loops and lines, positioned above the name Timothy Kamombo.

**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

Mr Neil McClements, resigned September 2024  
Mrs Sue Millman (Vice Chair)  
Ms Rebecca Middleton, co-opted February 2025  
Dr Shehla Mohammed  
Mrs Elizabeth Porterfield MBE (Chair)  
Mr David Ramsden (Treasurer and Chair of Finance and Governance Committee), until September 2024, and then co-opted until January 2025  
Mr Greg Stevenson  
Dr Sarah Wynn, until September 2024  
Dr Mike Winter, co-opted February 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](https://geneticalliance.org.uk)

Facebook [GeneticAllianceUK](https://www.facebook.com/GeneticAllianceUK)

X [GeneticAll\\_UK](https://twitter.com/GeneticAll_UK)

Instagram [GeneticAllianceUK](https://www.instagram.com/GeneticAllianceUK)

LinkedIn [Genetic Alliance UK](https://www.linkedin.com/company/GeneticAllianceUK)

## **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](http://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

**GENETIC ALLIANCE UK LTD****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 £
<b>Income from:</b>					
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
<b>Total income</b>		<u>542,042</u>	<u>343,811</u>	<u>885,853</u>	<u>780,935</u>
<b>Expenditure on:</b>					
Raising funds	4	81,691	-	81,691	111,653
Charitable activities	5	299,757	323,567	623,324	751,099
<b>Total expenditure</b>		<u>381,448</u>	<u>323,567</u>	<u>705,015</u>	<u>862,752</u>
<b>Net income/(expenditure)</b>	8	160,594	20,244	180,838	(81,817)
<b>Transfers between funds</b>	18	-	-	-	-
<b>Net movement in funds</b>		160,594	20,244	180,838	(81,817)
<b>Total funds at start of year</b>	18	29,712	12,134	41,846	123,663
<b>Total funds at end of year</b>	18	<u>190,306</u>	<u>32,378</u>	<u>222,684</u>	<u>41,846</u>

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

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

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

**GENETIC ALLIANCE UK LTD****BALANCE SHEET****AS AT 31 MARCH 2025**

Charity number: 1114195

Company number: 05772999

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

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

These financial statements were approved by the Trustees on 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

# GENETIC ALLIANCE UK LTD

## CASH FLOW STATEMENT

YEAR ENDED 31 MARCH 2025

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

### Cashflow Restrictions

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

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

# GENETIC ALLIANCE UK LTD

## NOTES TO THE FINANCIAL STATEMENTS

### YEAR ENDED 31 MARCH 2025

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#### 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.

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

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**1 Accounting policies (*continued*)**

**Expenditure**

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

***Raising funds***

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

***Charitable Activities***

Grants awarded are allocated to charitable activities.

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

***Governance costs***

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

***Allocation and apportionment costs***

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

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

***Redundancy costs***

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

***Pension costs and other post-retirement benefits***

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

***Fixed assets***

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

Depreciation is charged on assets at the following rates:

Office equipment - 3 years straight line

***Debtors***

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

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**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**

	<b>Unrestricted Funds</b>	<b>Restricted Funds</b>	<b>Total Funds 2025</b>
	<b>£</b>	<b>£</b>	<b>£</b>
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
<i>Grants from Government</i>			
National Lottery funding	-	97,078	97,078
Scottish Government	-	40,000	40,000
Other grants received	4,000	-	4,000
<i>Donations through fundraising:</i>			
Online donations	42,702	5,277	47,979
	<u>494,050</u>	<u>185,740</u>	<u>679,790</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

**2 Income from donations and legacies (*continued*)**

**Prior year**

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

**3 Income from: Charitable activities**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2025 £</b>
Consultancy work	47,108	158,071	205,179
	<u>47,108</u>	<u>158,071</u>	<u>205,179</u>

**Prior year**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

**4 Expenditure on: Raising funds**

	<b>Total Funds 2025 £</b>	<b>Total Funds 2024 £</b>
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
	<u>81,691</u>	<u>111,653</u>

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

**5 Expenditure on: Charitable activities**

	<b>Direct Costs £</b>	<b>Support Costs (Note 6) £</b>	<b>Total Funds 2025 £</b>
Membership and Engagement	145,357	88,032	233,389
Policy work	111,211	52,025	163,236
Research	119,045	107,654	226,699
	<u>375,613</u>	<u>247,711</u>	<u>623,324</u>
<b>Prior year</b>			
	<b>Direct Costs £</b>	<b>Support Costs (Note 6) £</b>	<b>Total Funds 2024 £</b>
Membership and Engagement	184,486	136,136	320,622
Policy work	151,707	160,271	311,978
Research	61,856	56,643	118,499
	<u>398,049</u>	<u>353,050</u>	<u>751,099</u>

£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.

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

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

	<b>Raising Funds £</b>	<b>Charitable Activities £</b>	<b>Total 2025 £</b>
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
	<u>3,202</u>	<u>247,711</u>	<u>250,913</u>

**Prior year**

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

**7 Governance costs**

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

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

This is stated after charging:

	<b>2025</b>	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
	<u>17,097</u>	<u>15,664</u>

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

**9 Staff costs and numbers**

The aggregate payroll costs were:

	<b>2025</b>	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
	<u>523,297</u>	<u>672,242</u>

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

	<b>2025</b>	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.

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

**11 Statement of Financial Activities comparative figures**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
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**12 Tangible fixed assets**

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

**13 Debtors**

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

**14 Creditors: amounts falling due within one year**

	<b>2025 £</b>	<b>2024 £</b>
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
	<u>192,204</u>	<u>153,354</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

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

	<b>2025</b>	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)
<b>Net cash inflow/(outflow) from operating activities</b>	<u><u>306,585</u></u>	<u><u>(52,632)</u></u>

**16 Analysis of changes in cash during the year**

	<b>2025</b>	2024	<b>Change</b>
	£	£	£
Cash at bank and in hand	<u>395,134</u>	<u>87,665</u>	<u>307,469</u>
	<b>2024</b>	2023	<b>Change</b>
	£	£	£
Cash at bank and in hand	<u>87,665</u>	<u>141,457</u>	<u>(53,792)</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

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**17 Analysis of changes in net debt**

	<b>1 April 2024 £</b>	<b>Cashflow Movements £</b>	<b>31 March 2025 £</b>
Cash at bank and in hand	87,665	307,469	395,134
	<u>87,665</u>	<u>307,469</u>	<u>395,134</u>
Prior year	<b>1 April 2023 £</b>	<b>Cashflow Movements £</b>	<b>31 March 2024 £</b>
Cash at bank and in hand	141,457	(53,792)	87,665
	<u>141,457</u>	<u>(53,792)</u>	<u>87,665</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

**18 Movement in Funds**

For the year ended 31 March 2025

	At 1 April 2024 £	Income £	Expenditure £	Transfers £	At 31 March 2025 £
<b>Restricted funds</b>					
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)	-	-
	<u>12,134</u>	<u>343,811</u>	<u>(323,567)</u>	<u>-</u>	<u>32,378</u>
<b>Unrestricted funds</b>					
General funds	29,712	175,551	(205,683)	190,726	190,306
<b>Designated funds</b>					
Rare Disease Day	-	92,210	(92,210)	-	-
Rare Disease UK General Donations	-	274,281	(83,555)	(190,726)	-
	<u>29,712</u>	<u>542,042</u>	<u>(381,448)</u>	<u>-</u>	<u>190,306</u>
<b>Total funds</b>	<u>41,846</u>	<u>885,853</u>	<u>(705,015)</u>	<u>-</u>	<u>222,684</u>

**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.

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

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**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.

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2025**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
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**19 Analysis of net assets between funds**

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

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

**20 Related party transactions**

There are no transactions with trustees or other related parties other than those disclosed as required by the SORP elsewhere in the financial statements. No balances were due to or from related parties at the



Genetic Alliance UK – [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk) – [geneticalliance.org.uk](http://geneticalliance.org.uk)

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

**GENETIC ALLIANCE UK LTD**

England & Wales - Charity number 1114195

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# Accounts

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

**GENETIC ALLIANCE UK**

**Financial statements for the year ended 31 March 2024**

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## Report of the Trustees

### For the year ended 31 March 2024

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

The Trustees have adopted the provision of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

### Background

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

#### Genetic and rare conditions in numbers

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

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

## Summary of Annual Performance 2024

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

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

### Objectives and aims

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

The objectives of the charity are to:

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

We run two long-standing projects:

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

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit, and have complied with their duty under section 4 of the Charities Act 2021 when reviewing the charity's aims and objectives and in implementing current and future planning activities.

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

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

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

Our objectives (how we will do it) are:

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

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

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

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

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

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

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

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

## 1. Growing our alliance and supporting our members

### Building a growing and diverse alliance

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

### New members and improved opportunities for engagement

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

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

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

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

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

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

## Our new website

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

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

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

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

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

### Driving progress on UK Rare Diseases Framework

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

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

### Working in partnership to deliver the Rare Disease Research UK Platform

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

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

### Maximising opportunities to raise awareness on Rare Disease Day 2024

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

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

### **Central source of data about rare conditions**

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

### **Policy report to drive better understanding of data**

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

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

### **Factsheets to raise awareness of key facts and figures**

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

### **Raising awareness through the media**

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

### **Raising awareness at Parliamentary receptions**

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

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

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

### **Raising awareness among healthcare professionals and the public**

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

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

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

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

### **A strong legacy for future advocacy**

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

### **Rare Resources guides**

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

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

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

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

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

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

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

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

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

#### Raising awareness through the media of issues important to our members

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

#### Helping our members to engage with elected representatives across the UK

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

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

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

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

### **Ensuring patient voices are heard by decision-makers**

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

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

### **Shared learning roundtable for members on Managed Access Agreements**

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

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

### Making sure individuals and families benefit from genomic breakthroughs

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

### Supporting the development of pilot SWAN clinics

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

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

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

### SWAN UK

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

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

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

### **Undiagnosed Children's Day 2023**

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

### **Working in partnership with the Wales Gene Park**

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

### **Equity of access to cell and gene therapies**

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

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

### Supporting research on new approaches to genomic screening

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

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

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

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

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

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

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

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

### **Raising awareness of international best practice**

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

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

## This year and the coming year

### Delivering the 2023/24 Business Plan

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

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

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

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

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

### Looking forward to 2024/25

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

During 2024/25 our business plan will focus on:

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

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

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

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

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

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

## **Thank you to our supporters and funders**

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

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

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

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

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

## Treasurer's letter and financial review

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

### Review of the financial position

#### Income

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

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

#### Expenditure

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

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

#### Surplus/deficit

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

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

#### Reserves policy

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

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

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

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

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

## Conclusion

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

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

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

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



**David Ramsden**  
**Treasurer, Board of Trustees**

## Structure, governance and management

### Constitution

Genetic Alliance UK is the trading name for Genetic Alliance UK Ltd, a registered charity and a company limited by guarantee, incorporated on 6 April 2006 and governed by its Memorandum and Articles of Association.

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

### Appointment and training of Trustees

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

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

### Governance and organisational management

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

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

Trustees delegate certain powers in connection with the charity's management, remuneration (related to responsibility and market comparisons) and administration to the Finance and Governance (F&G) committee which met six times during 2023/24. The F&G committee provides detailed oversight and advice to the Board of Trustees in relation to financial management, financial viability, risk management and governance. The F&G committee has a minimum of three Trustee members, appointed from and by the Board of Trustees that includes the Treasurer (Chair of the Committee), Chair of Genetic Alliance UK, and the Deputy Chair. The Chief Executive and Directors of Genetic Alliance UK are ex officio.

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

### Risk management

Trustees have considered the major risks to which the charity is exposed and have established procedures including a risk register to identify and manage those risks. All risks are reviewed at each meeting of the Board of Trustees and by the F&G committee. The main risks the charity has identified are the low level of unrestricted funds, due to volatile charitable giving, and the cash flow issues this may cause. The charity has taken measures to reduce its cost base, and to find new sustainable forms of funding. In particular, the charity has built an ongoing relationship with funders who can support

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

### **Fundraising**

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

### **Working with the life-sciences industry**

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

## Reference and administrative detail

### Governing document

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

### Registered company number

05772999

### Registered charity numbers

1114195 and SC039299

### Registered office

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

### Postal address

3<sup>rd</sup> Floor, 86-90 Paul Street, London EC2A 4NE

### Trustees

Ms Lara Bloom (joined September 2023)

Ms Gloria Clark (Chair of People and Policy Committee)

Ms Phillippa Farrant

Mr Toby Hannam (joined September 2023)

Miss Sara Hunt

Mr Neil McClements

Mrs Sue Millman (Vice Chair)

Dr Shehla Mohammed (joined September 2023)

Mrs Elizabeth Porterfield MBE (Chair)

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

Mr Greg Stevenson (joined September 2023)

Dr Sarah Wynn

### Board observer

Robin Nott

### Chief Executive Officer

Louise Fish

### Senior Management Team

Dr Amy Hunter, Nick Meade, Mary Edwards

### Auditors

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

### Management accountant

Fiona Bevan of Bevan Financial Management Ltd

### Bankers

CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ

HSBC, Lion House, 25 Islington High Street, London N1 9LJ

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

<b>Website</b>	geneticalliance.org.uk
<b>Facebook</b>	GeneticAllianceUK
<b>Twitter</b>	GeneticAll_UK
<b>Instagram</b>	GeneticAllianceUK
<b>LinkedIn</b>	Genetic Alliance UK

## Trustee responsibility

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

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

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

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

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006.

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

In so far as the Trustees are aware:

- There is no relevant audit information of which the charitable company's auditors are unaware.
- The Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

## Auditors

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

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



**Elizabeth Porterfield**  
Chair, Board of Trustees

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

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

#### Opinion

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

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2024, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustees' Investment (Scotland) Act 2005 and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (amended).

#### Basis for opinion

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

#### Conclusions relating to going concern

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

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

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

## **Other information**

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

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

We have nothing to report in this regard.

## **Opinions on other matters prescribed by the Companies Act 2006**

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

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

## **Matters on which we are required to report by exception**

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

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of directors' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemption in preparing the Report of the Board of Trustees and Accounts.

## **Responsibilities of trustees**

As explained more fully in the trustees' responsibilities statement set out on page 26 the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

## **Auditor's responsibilities for the audit of the financial statements**

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

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

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

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

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

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

### Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



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

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

Date: 30 July 2024

# GENETIC ALLIANCE UK LTD

## STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME AND EXPENDITURE ACCOUNT)

YEAR ENDED 31 MARCH 2024

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

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

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

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

# GENETIC ALLIANCE UK LTD

## BALANCE SHEET

AS AT 31 MARCH 2024

Company number: 05772999

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

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

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

Elizabeth Porterfield, MBE  
Chair of Trustees

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

# GENETIC ALLIANCE UK LTD

## CASH FLOW STATEMENT

YEAR ENDED 31 MARCH 2024

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

### Cashflow Restrictions

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

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

# GENETIC ALLIANCE UK LTD

## NOTES TO THE FINANCIAL STATEMENTS

### YEAR ENDED 31 MARCH 2024

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#### 1 Accounting policies

##### Accounting convention

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

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

##### Going concern

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

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

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

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

##### Income

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

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

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

Membership income is accounted for as receivable.

Investment income is included on a receivable basis.

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

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

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**1 Accounting policies (*continued*)**

**Expenditure**

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

***Raising funds***

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

***Charitable Activities***

Grants awarded are allocated to charitable activities.

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

***Governance costs***

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

***Allocation and apportionment costs***

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

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

***Redundancy costs***

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

***Pension costs and other post-retirement benefits***

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

***Fixed assets***

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

Depreciation is charged on assets at the following rates:

Office equipment - 3 years straight line

***Debtors***

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

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

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**1 Accounting policies (*continued*)**

**Cash**

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

**Creditors**

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

**Fund accounting**

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

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

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

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

**2 Income from donations and legacies**

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

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

**2 Income from donations and legacies (*continued*)**

**Prior year**

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

**3 Income from: Charitable activities**

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

**Prior year**

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

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

**4 Expenditure on: Raising funds**

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

**5 Expenditure on Charitable activities**

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

**Prior year**

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

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

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

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

**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:

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

**Prior year**

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

**7 Governance costs**

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

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

**8 Net income/(expenditure) for the year**

This is stated after charging:

	<b>2024</b>	2023
	£	£
Auditor's remuneration - for audit services	10,800	9,000
Trustees' travel expenses (4 trustees, 2023: 3 trustees)	2,419	2,325
Depreciation	2,445	662
	<u>15,664</u>	<u>12,000</u>

No Trustee received any remuneration during the year.

**9 Staff costs and numbers**

The aggregate payroll costs were:

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

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

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

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

**10 Taxation**

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

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

**11 Statement of Financial Activities comparative figures**

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

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

**12 Tangible fixed assets**

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

**13 Debtors**

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

**14 Creditors: amounts falling due within one year**

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

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

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

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

**16 Analysis of changes in cash during the year**

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

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

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**17 Analysis of changes in net debt**

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

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

**18 Movement in Funds**

For the year ended 31 March 2024

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

**Fund descriptions**

**Restricted funds**

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

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

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

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

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

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**18 Movement in funds (continued)**

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

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

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

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

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

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

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

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

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

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

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

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

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

**SWAN UK Scotland** - funds received for outreach in Scotland

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

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

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

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

**Designated funds**

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

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

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

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

**18 Movement in funds (continued)**

For the year ended 31 March 2023

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

**19 Analysis of net assets between funds**

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

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

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**19 Analysis of net assets between funds (continued)**

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

**20 Related party transactions**

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

**GENETIC ALLIANCE UK LTD**

England & Wales - Charity number 1114195

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# Accounts

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

**GENETIC ALLIANCE UK**

**Financial statements for the year ended 31 March 2023**

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## Report of the Trustees

### For the year ended 31 March 2023

The Trustees, who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statement of the charity for the year ended 31 March 2023.

The Trustees have adopted the provision of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

### Background

Genetic Alliance UK is an alliance of over 230 charities and support groups. We have a thirty-year track record of working together to improve the lives of people in the UK living with lifelong and complex genetic and rare conditions.

### Genetic and rare conditions in numbers

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

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

## Summary of Annual Performance 2023

During 2022/23 Genetic Alliance UK continued to deliver on our strategic priorities:

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

## Objectives and aims

Genetic Alliance UK is an alliance of over 230 charities and support groups working together to improve the lives of people living with genetic and rare conditions.

The objectives of the charity are to:

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

We run two long-standing projects:

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

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

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

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit, and have complied with their duty under section 4 of the Charities Act 2021 when reviewing the charity's aims and objectives and in implementing current and future planning activities.

## 1. Growing our alliance and supporting our members

### Building a growing and diverse alliance

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

We keep membership fees as low as possible to maximise the number of organisations working together to improve the lives of people living with genetic and rare conditions. Three out of 10 of our members are micro charities who have free membership (annual income under £10,000). A further five out of 10 of our members are small charities with membership fees of £50 each year (annual income under £250,000).

### New members and improved opportunities for engagement

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

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

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

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

### Building Rare Resilience

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

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

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

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

### **Research projects for members**

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

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

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

### UK Rare Diseases Framework

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

### Maximising opportunities to raise awareness on Rare Disease Day 2023

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

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

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

### Rare Resources Scotland

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

### **Rare Resources Cymru**

We published Rare Resources Cymru in December 2022 and began to disseminate the resources to key health and education professionals across Wales. The bilingual toolkit is a collection of information guides for families who have recently received a diagnosis of a genetic or rare condition, are on the journey to receive a diagnosis or have been told their child's condition is so rare they may not get a diagnosis. The resources have been developed and produced by Genetic Alliance UK in collaboration with families in Wales.

### **Mental health paper**

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

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

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

### **Healthcare Professionals Project – Scotland**

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

### **Advanced therapies**

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

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

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

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

#### **Using high profile opportunities to contribute the views of our members**

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

#### **Providing a platform for patient voice**

Genetic Alliance UK are the secretariat for the All Party Parliamentary Group and Cross Party Groups for rare, genetic and undiagnosed conditions in Westminster, the Senedd and Holyrood. Over the past year we've had a total of seven meetings across the three groups, one parliamentary exhibition in Scotland and we also host genomics cafés every six weeks in Wales. Across all of these events we have invited 16 individuals to share their lived experiences directly with parliamentarians, policy makers and healthcare professionals.

#### **Raising awareness with elected representatives**

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

#### **Influencing legislation**

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

#### **Ensuring patient voice is involved in decision making and policy development**

We continually respond to a variety of consultations from the governments across the UK, healthcare and fertility regulators, healthcare delivery partners and other bodies, ensuring that the voices of our members and the rare community are involved in any decision making or policy development relevant to our community. Over the past year we have engaged with members and responded to a total of 21 National Institute of Health and Care Excellence (NICE) scoping consultations, submitted patient perspective statements to the Human Fertilisation and Embryology Authority (HFEA) as evidence for 37 preimplantation genetic testing license requests, and responded to a further 31 consultations by UK governments and the NHS on a variety of topics.

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

### Encouraging investment in clinical research programmes and clinical genetics services

Science is making great strides forward in genomics. However, people affected by genetic conditions and their families will only benefit from this science if the UK also invests in clinical research programmes and NHS clinical genetics services. We used a high-profile opportunity speaking on a keynote panel at the NHS Genomics Healthcare Summit to raise awareness of the need to make sure that findings from research projects and day-to-day clinical practice are shared with individuals and families in a timely way to help them make informed decisions about life-long treatment and care.

### Welsh Rare Disease Action Plan – The SWAN Clinic

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

### SWAN UK

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

### SWAN UK – Cymru

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

### Undiagnosed Children's Day 2022

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

### **Mental health support for the SWAN UK Community**

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

### **Genomics Delivery Plan for Wales – published in December 2022**

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

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

### **Citizens' Jury on Genome Editing of Human Embryos**

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

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

### **Raising awareness of the need to start building new screening programmes**

Some of the appetite for genomic screening from families living with genetic and rare conditions is because the UK is not extracting all of the potential from its conventional newborn and populations screening programmes. For example, the newborn bloodspot ‘heelprick’ test given to every newborn baby in the UK currently screens for a maximum of 9 conditions, but there are more than 20 European countries screening for more than the UK, with most of those screening for 20 conditions or more. We have raised awareness of this issue through ‘letters to the editor’ to national newspapers and senior-level meetings with the Department of Health and NHS.

### **Highlighting the challenges on the silver screen**

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

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

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

### **Raising awareness of international best practice**

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

### **Supporting research on new approaches to genomic screening**

We work closely with Genomics England to inform the development of their new research programme focused on whole genome sequencing, the Newborn Screening Programme. Genomics England regularly join our member briefings to keep our community updated on the project’s progress, and we sit on their Ethics Working Group. We are exploring how we can best support their new working group on communicating results and onward support, which will meet in 2023/24. This gives us the opportunity to ensure those crucial first moments on a rare condition journey are delivered appropriately, with a balanced and informative approach to introducing new parents to the risk that their child may develop a rare condition. We hope to be able to bring the expertise of our member organisations who already receive ‘screen positive’ messages through the newborn bloodspot ‘heelprick’ programme to this development process.

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

## The year ahead

### 2023/24 Business Plan

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

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

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

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

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

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

### New five-year strategy 2024-29

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

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

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

Our objectives (how we will do it) are:

- Influencing national policy and provision where it matters most by:
  - Championing timely diagnosis and better coordinated care and treatment for people living with genetic and rare conditions.

- Making sure an understanding of what is most important to people living with genetic and rare conditions shapes research, policy, regulation, practice and the development of new medicines and therapies.
- Ensuring scientific breakthroughs in genomics reach people living with genetic conditions in a timely fashion through research programmes and routine diagnostic and clinical services.
- Promoting opportunities to expand newborn and population screening for genetic and rare conditions in line with international best practice.
- Making sure our influencing drives action across both policy and practice.
- Tracking how people with genetic and rare conditions are affected by this action across the four nations.

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

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

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

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

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

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

## **Thank you to our supporters and funders**

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

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

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

Albireo  
Alexion  
Amicus Therapeutics  
BioCryst  
Biogen  
Chiesi  
The Arnold Clarke Foundation  
CSL Behring  
EUSA Pharma  
Gilead  
Incyte  
Janssen  
Kyowa Kirin  
The Robert Luff Foundation  
The National Lottery Community Fund  
Novartis  
Orchard Therapeutics  
P F Charitable Trust  
Pfizer  
PTC Therapeutics  
Roche  
Sanofi  
Takeda  
Topek Southern Ltd (TSL)  
Trisomy 9 Mosaic Trust  
UCB  
Vertex  
The Wellcome Trust

## **Treasurer's letter and financial review**

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

### **Review of the financial position**

#### **Income**

The results for the year are set out in the statement of financial activities on page 27. The total income for the year was £741,859 (£713,568 in 2022).

This represents an overall increase of 4%, however, this was not experienced evenly across all sources of income. General fundraising remains challenging, which has emphasized the importance of our trust and foundation, corporate and government funders. I would particularly like to note the contribution from the Wellcome Trust, which has helped to ensure our organisational resilience.

#### **Expenditure**

Total expenditure for the year was £769,204 (£762,424 in 2022).

This represents less than a 1% increase on the prior year and reflects a continued focus on cost control. The mix of expenditure remained consistent over the period with policy work at 42%, membership and engagement at 37%, research at 8% and raising funds at 12%, which means 88% of our spending is on charitable activities.

#### **Surplus/deficit**

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

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

#### **Reserves policy**

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

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

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

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

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

## Conclusion

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

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

As noted on page 30 the Board of Genetic Alliance UK are mindful that the charity is likely to continue to operate in an environment of economic uncertainty and challenge and have reviewed budgets and forecasts for the next 12 months on that basis. This work, informed by prudent assumptions, indicates that the charity will break even for the year ending 31 March 2024 and that adequate liquid resources will continue to be available to fund the activities of the charity for the foreseeable future.

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

A handwritten signature in black ink, appearing to read 'David Ramsden', with a stylized flourish at the end.

**David Ramsden**  
**Treasurer, Board of Trustees**

## **Structure, governance and management**

### **Constitution**

Genetic Alliance UK is the trading name for Genetic Alliance UK Ltd, a registered charity and a company limited by guarantee, incorporated on 6 April 2006 and governed by its Memorandum and Articles of Association.

In 2023/24 we plan to update the Memorandum and Articles in line with best practice for trustee length of service, membership eligibility criteria and codes of conduct for trustees and members.

### **Appointment and training of Trustees**

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

In 2023/24 we plan to recruit up to four new trustees to increase the independence and diversity of the Board.

### **Governance and organisational management**

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

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

Trustees delegate certain powers in connection with the charity's management, remuneration (related to responsibility and market comparisons) and administration to the Finance and Governance (F&G) committee which met four times in the year. The F&G committee provides detailed oversight and advice to the Board of Trustees in relation to financial management, financial viability, risk management and governance. The F&G committee has a minimum of three Trustee members, appointed from and by the Board of Trustees that includes the Treasurer (Chair of the Committee), Chair of Genetic Alliance UK, and the Deputy Chair. The Chief Executive and Directors of Genetic Alliance UK are ex officio.

In 2023/24 we plan to introduce a new People and Policies (P&P) committee chaired by a nominated Trustee which will meet at least two times a year to oversee recruitment of trustees and senior staff, human resources policies, pay and reward, and policies on issues such as GDPR, health and safety, and safeguarding.

### **Risk management**

Trustees have considered the major risks to which the charity is exposed and have established procedures including a risk register to identify and manage those risks. All risks are reviewed at each meeting of the Board of Trustees and by the F&G committee.

## **Fundraising**

Genetic Alliance UK undertakes most of its fundraising activities in-house, but used a consultant during 2022/23 solely for the purpose of large grant applications. Genetic Alliance UK is registered with the Fundraising Regulator and adheres to the codes of ethics laid out by the Fundraising Regulator and The Code of Fundraising practice in relation to all fundraising activities. The charity received no complaints about its fundraising practice in this financial year.

## **Working with the life-sciences industry**

Genetic Alliance UK receives support from industry partners for projects that help us to deliver our charitable objectives. During 2022/23 we updated our policy on working with industry to set out clear principles and guidance for how we work with the life-sciences industry: [geneticalliance.org.uk/policies/working-with-industry-policy/](https://geneticalliance.org.uk/policies/working-with-industry-policy/).

## Reference and administrative detail

### Governing document

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

### Registered company number

05772999

### Registered charity numbers

1114195 and SC039299

### Registered office

Creative Works, 7 Blackhorse Lane, London E17 6DS

### Trustees

Ms Gloria Clark

Ms Phillippa Farrant

Miss Sara Hunt

Dr Celine Lewis (resigned May 2022)

Mr Neil McClements

Mrs Sue Millman (Vice Chair)

Mrs Elizabeth Porterfield (Chair)

Mr David Ramsden (Treasurer)

Dr Susan Walsh (completed terms as trustee September 2022)

Mrs Julie Wooton (resigned February 2023)

Dr Sarah Wynn

### Board observer

Robin Nott

### Chief Executive Officer

Nick Meade and Lauren Roberts (Interim Chief Executives until June 2022)

Louise Fish (joined July 2022)

### Senior Management Team

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

### Auditors

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

### Management accountant

Fiona Bevan Financial Management

### Bankers

CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ

HSBC, Lion House, 25 Islington High Street, London N1 9LJ

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

<b>Website</b>	geneticalliance.org.uk
<b>Facebook</b>	GeneticAllianceUK
<b>Twitter</b>	GeneticAll_UK
<b>Instagram</b>	GeneticAllianceUK
<b>LinkedIn</b>	Genetic Alliance UK

## Trustee responsibility

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

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

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

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

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006.

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

In so far as the Trustees are aware:

- There is no relevant audit information of which the charitable company's auditors are unaware.
- The Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

## Auditors

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

Report of the Trustees, incorporating a strategic report, approved by order of the Board of Trustees, as the company directors on 27 July 2023 and signed on the Board's behalf by:



**Elizabeth Porterfield**  
**Chair, Board of Trustees**

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

### Opinion

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2023 set out on pages 27 to 44 which comprise the statement of financial activities, the balance sheet, the cash flow statement and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2023, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustees' Investment (Scotland) Act 2005 and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (amended).

### Basis for opinion

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

### Conclusions relating to going concern

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

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

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

### Other information

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

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

We have nothing to report in this regard.

### **Opinions on other matters prescribed by the Companies Act 2006**

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

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

### **Matters on which we are required to report by exception**

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

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of directors' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemption in preparing the Report of the Board of Trustees and Accounts.

### **Responsibilities of trustees**

As explained more fully in the trustees' responsibilities statement set out on page 22 the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

## **Auditor's responsibilities for the audit of the financial statements**

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

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

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

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

We focussed on laws and regulations which could give rise to a material misstatement in the financial statements, including, but not limited to, the Companies Act 2006.

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

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

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

## Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



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

**Nyman Libson Paul LLP**

Chartered Accountants

Registered Auditors

124 Finchley Road

London

NW3 5JS

Date: 27 July 2023

# GENETIC ALLIANCE UK LTD

## STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME AND EXPENDITURE ACCOUNT)

YEAR ENDED 31 MARCH 2023

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

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

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

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

# GENETIC ALLIANCE UK LTD

## BALANCE SHEET

AS AT 31 MARCH 2023

Company number: 05772999

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

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

These financial statements were approved by the Trustees on 27 July 2023 and are signed on their behalf by:



Elizabeth Porterfield  
Chair of Trustees

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

# GENETIC ALLIANCE UK LTD

## CASH FLOW STATEMENT

YEAR ENDED 31 MARCH 2023

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

### Cashflow Restrictions

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

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

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**1 Accounting policies**

**Accounting convention**

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

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

**Going concern**

Like many organisations, Genetic Alliance UK continued to face a challenging environment in 2022/23 with financial volatility and the cost of living crisis depressing charitable donations and placing inflationary pressure on costs. However, any adverse effects were countered by the careful planning and budgeting.

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

The Trustees are mindful that they are likely to continue to operate in an environment of economic uncertainty and challenge and have reviewed budgets and forecasts for the next 12 months on that basis. This work, informed by prudent assumptions, indicates that the Charity will break even for the year ending 31 March 2024 and that adequate liquid resources will continue to be available to fund the activities.

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

**Income**

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

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

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

Membership income is accounted for as receivable.

Investment income is included on a receivable basis.

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

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**1 Accounting policies (*continued*)**

**Expenditure**

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

**Raising funds**

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

**Charitable Activities**

Grants awarded are allocated to charitable activities.

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

**Governance costs**

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

**Allocation and apportionment costs**

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

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

**Pension costs and other post-retirement benefits**

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

**Fixed assets**

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

Depreciation is charged on assets at the following rates:

Office equipment - 3 years straight line

**Debtors**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

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**1 Accounting policies (continued)**

**Cash**

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

**Creditors**

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

**Fund accounting**

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

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

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

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

**2 Income from donations and legacies**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**2 Income from donations and legacies (*continued*)**

**Prior year**

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

**3 Income from: Charitable activities**

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

**Prior year**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2022 £</b>
Consultancy work	56,114	-	56,114
	<u>56,114</u>	<u>-</u>	<u>56,114</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**4 Expenditure on: Raising funds**

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

**5 Expenditure on Charitable activities**

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

**Prior year**

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

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

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**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:

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

**Prior year**

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

**7 Governance costs**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**8 Net income/(expenditure) for the year**

This is stated after charging:

	<b>2023</b>	2022
	£	£
Auditor's remuneration - for audit services	9,000	8,100
Trustees' travel expenses (3 trustees, 2022: 2 trustees)	2,325	884
Depreciation	662	286
	<u>12,000</u>	<u>9,270</u>

No Trustee received any remuneration during the year.

**9 Staff costs and numbers**

The aggregate payroll costs were:

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

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

	<b>2023</b>	2022
Between £60,001 and £70,000	-	1
Between £70,001 and £80,000	<u>1</u>	<u>-</u>

The average weekly number of employees during the year was 16 (2022: 17), calculated on the basis of average headcount. The total employment benefits received by key management personnel including employer's national insurance and employer's pension contributions were £173,181 (2022: £181,356).

**10 Taxation**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**11 Statement of Financial Activities comparative figures**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**12 Tangible fixed assets**

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

**13 Debtors**

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

**14 Creditors: amounts falling due within one year**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

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

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

**16 Analysis of changes in cash during the year**

	<b>2023</b> £	2022 £	<b>Change</b> £
Cash at bank and in hand	<u>141,457</u>	<u>199,282</u>	<u>(57,825)</u>
	<b>2022</b> £	2021 £	<b>Change</b> £
Cash at bank and in hand	<u>199,282</u>	<u>239,896</u>	<u>(40,614)</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

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**17 Analysis of changes in net debt**

	<b>1 April 2022 £</b>	<b>Cashflow Movements £</b>	<b>31 March 2023 £</b>
Cash at bank and in hand	199,282	(57,825)	141,457
	<u>199,282</u>	<u>(57,825)</u>	<u>141,457</u>
Prior year	<b>1 April 2021 £</b>	<b>Cashflow Movements £</b>	<b>31 March 2022 £</b>
Cash at bank and in hand	239,896	(40,614)	199,282
	<u>239,896</u>	<u>(40,614)</u>	<u>199,282</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**18 Movement in Funds**

For the year ended 31 March 2023

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

**Fund descriptions**

**Restricted funds**

**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)

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

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

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

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

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**18 Movement in funds (*continued*)**

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

**SWAN UK Scotland** - funds received for outreach in Scotland

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

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

**Building Rare Resilience** - This was the second instalment of restricted funding from the National Lottery Covid-19 emergency fund for the Building Rare Resilience project.

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

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

**Rare Resources** - funds are restricted to the development and dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions.

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

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

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

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

**Rare Disease Day** - funds received to help with the costs of putting on our annual Rare Disease Day.

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

**Designated funds**

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

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

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

**18 Movement in funds (continued)**

For the year ended 31 March 2022

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

**19 Analysis of net assets between funds**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2023**

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**19 Analysis of net assets between funds (continued)**

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

**20 Related party transactions**

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

**GENETIC ALLIANCE UK LTD**

England & Wales - Charity number 1114195

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# Accounts

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# GENETIC ALLIANCE UK

Report of the Board of Trustees and Accounts  
2021-2022



**GENETIC  
ALLIANCE UK**

# REPORT OF THE BOARD OF TRUSTEES

for the year ended 31 March 2022

**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 2022. The trustees have adopted the provisions of the 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 second edition January 2019) and the Companies Act 2006.**

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### Genetic Alliance UK

[contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

[geneticalliance.org.uk](http://geneticalliance.org.uk)

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

# WELCOME FROM THE CHAIR



Following the publication of the UK Rare Diseases Framework at the start of the year, 2021/22 was a crucial year for Genetic Alliance UK and our community.

The Framework brings together many of our priorities including diagnosis, screening, and coordination of care. Throughout the year, we have engaged closely with the development of genomic medicine and the myriad of opportunities to improve access to medicines for rare conditions. We have put significant resources into making sure there are as many voices of people living with genetic, rare and undiagnosed conditions as possible feeding into the four nations' Framework implementation plans.

It is particularly important that I take this opportunity to thank our interim joint Chief Executives, Nick Meade, Director of Policy, and Lauren Roberts, Director of Engagement and Support for giving us the continuity and stability needed during and after the pandemic. Their commitment gave us the space and time needed to determine how to take forward the Chief Executive role for the longer term. Their unstinting efforts – and alongside them those of the rest of our amazing team – ensured that not only have we come through the most challenging of times, but we have yet again produced a range of reports and services for our members that can only be

considered outstanding when viewed against the significance of the pandemic and the changed financial and fundraising background. It is thanks to all these efforts that we can look forward with renewed enthusiasm to working together on behalf of everyone affected by a genetic, rare or undiagnosed condition.

While this report is rightly and predominantly a retrospective of the past year it is also important that we look forward. At the time of writing we have recently been joined by our new Chief Executive, Louise Fish, who joins us from the Tuberous Sclerosis Association, just one of our many member organisations. Welcome, Louise.

While Louise's priority is to set Genetic Alliance UK's strategic direction and day to day focus for the next five years, our passion, as always, is to champion the voices of 3.5 million people living with genetic, rare and undiagnosed conditions in the UK.

The Board of Trustees and I very much look forward to working with all of you to drive our vision.

A handwritten signature in blue ink, which appears to read 'Elizabeth Porterfield'.

**Elizabeth Porterfield**  
Chair  
Genetic Alliance UK

## Rupert's story

At just eight weeks old, our gorgeous boy Rupert was diagnosed with SMA Type 1B (Spinal Muscular Atrophy). SMA is a rare genetic neuromuscular condition that causes muscle weakness and wasting due to the loss of motor neurons.

Around 45 children are born with SMA Type 1 each year in the UK. Many doctors are not aware of the disease, which delays diagnosis. Every day is crucial, especially in Type 1 babies, where motor neurons die every minute.

Rupert was given a life expectancy of just seven months without treatment. He had deteriorated significantly in a matter of days, and there was a concern his liver was too weak for treatment.

Thankfully Rupert passed the criteria and became the second baby in London to be treated with Zolgensma, a gene therapy that replaces the defunct SMN1 gene. Zolgensma uses harmless, genetically engineered viruses to deliver functioning SMN1 genes, in order to increase SMN protein levels.

# OBJECTIVES AND AIMS

**Genetic Alliance UK champions the voices of people living with a genetic, rare or undiagnosed condition in the UK, their families, and the amazing charities and support groups that advocate for them. We are an alliance of over 200 patient organisations.**

## **The objectives of the charity:**

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

We advocate for fast and accurate diagnosis, good quality care and access to the best treatments. We actively support progress in research and engage with decision makers and the public about the challenges faced by our community.

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, and to ensure that people and families living with rare conditions have access to a final diagnosis, coordinated care and specialist care and treatment. Rare Disease UK is the official organiser of Rare Disease Day in the UK.
- **SWAN UK** (syndromes without a name), the only dedicated support network in the UK for families affected by a syndrome without a name – a genetic condition so rare it often remains undiagnosed.

Genetic Alliance UK's vision is a society in which people affected by genetic, rare and undiagnosed conditions receive excellent care and are

empowered and supported in all aspects of their lives.

Our five-year strategy from 2018 to 2023 sets out a clear mission to work with organisations and individuals to ensure that the needs and preferences of all people affected by genetic, rare and undiagnosed conditions are recognised, understood and met. We have four strategic objectives:

- Driving progress
- Building our community
- Building greater awareness
- Building our organisation.

You can read our 2018 to 2023 strategy at [www.geneticalliance.org.uk/our-strategy/](http://www.geneticalliance.org.uk/our-strategy/)

We will begin reviewing this strategy in Autumn 2022, ready to approve a new five-year strategy in Autumn 2023 that will inform our business planning for 2024 and into the future.

## **Public benefit**

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit and have complied with their duty under section 4 of the Charities Act 2011 when reviewing the charity's aims and objectives; and in implementing current and planning future activities.



# ABOUT GENETIC, RARE AND UNDIAGNOSED CONDITIONS

While genetic, rare and undiagnosed conditions are individually rare, taken together there are around 3.5 million people living with these conditions in the UK. This compares with 900,000 people who live with Alzheimer's disease in the UK and around 375,000 new cancer cases in the UK every year.

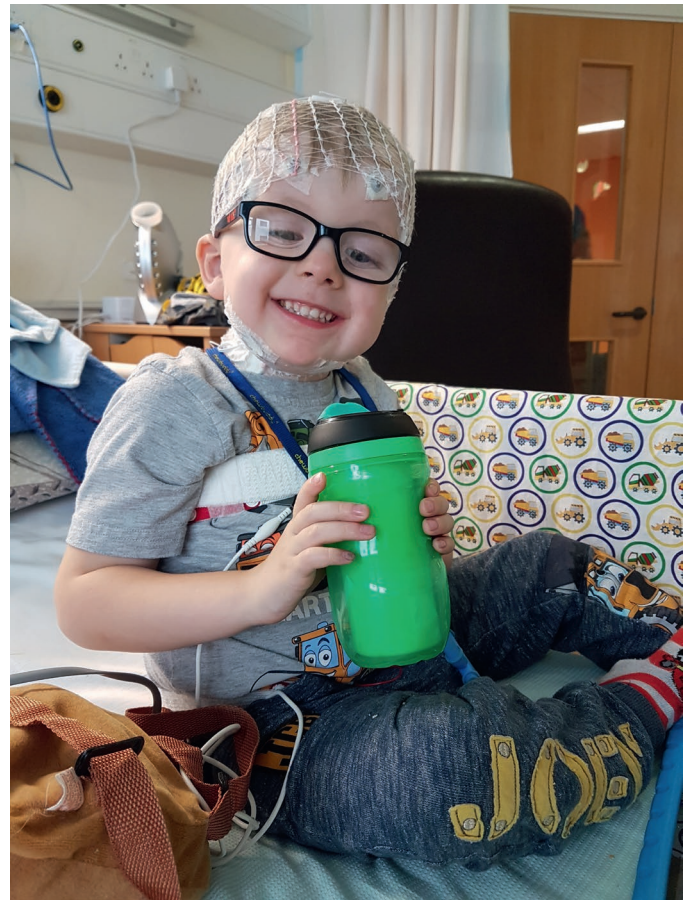
A **genetic condition** is one that is caused by a change in an individual's genome. The most common genetic conditions such as sickle cell disease affect around 15,000 people in the UK, with 300 babies born with the condition each year. The rarest genetic conditions may affect just one family in the UK, and there may only be a handful of people affected across the globe.

A **rare condition** affects fewer than 1 in 2,000 people. There are over 6,000 known rare conditions which can be life threatening and take longer to diagnose and treat than more common conditions. Eight out of 10 rare diseases have a genetic origin.

An **undiagnosed condition** is known as a 'syndrome without a name' or SWAN. Each year around 6,000 children are born in the UK with a genetic condition so rare that it does not yet have a name. This might be because the right test has not been developed to diagnose it, or the genetic cause of the condition has not yet been discovered.

Genetic, rare and undiagnosed conditions are often life-limiting and life-threatening. Seven out of 10 rare diseases affect children, and sadly more than three out of 10 children with a rare disease die before their fifth birthday.

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



# MAKING PROGRESS: THE UK RARE DISEASES FRAMEWORK

Despite Covid-19 continuing to take up a large amount of bandwidth in national policy priorities and the health service budget, we were delighted to enter this year with a new UK Rare Diseases Framework published in early 2021 by the UK governments. You can find the UK Rare Diseases Framework at [www.gov.uk/government/publications/uk-rare-diseases-framework](http://www.gov.uk/government/publications/uk-rare-diseases-framework).

The 2021 UK Rare Disease Framework set out the commitment of UK governments to improve the lives of people with rare conditions over the next five years. The Framework focuses on four priorities identified in Genetic Alliance UK's Rare Experience 2020 report, which are faster diagnosis, increased awareness of rare diseases, better coordination of care, and improving access to specialist care, treatments and drugs.

Genetic Alliance UK's report paints a detailed and vivid picture of a wide range and variety of experiences of people living with rare conditions in the UK. It was structured to match our expected themes of the incoming UK Framework for rare conditions, and included recommendations and learning points for the future of rare disease policy in the UK.

The publication of the Framework was the product of hard work by supporters of our Rare Disease UK campaign and thanks to the commitment of the whole multi-stakeholder rare conditions community. Our key aim this year has been to build on this opportunity, ensuring the voice of people living with rare conditions is heard loud and clear in the development of each individual Rare Disease Framework action plans for England, Scotland, Wales and Northern Ireland.

Both England and Northern Ireland's action plans were published by the end of March 2022. Well-informed and vocal members of the rare condition community are sitting on the relevant committees and working groups. Our work to support the development of a strong and deliverable action plan for each nation is set out throughout this report.

# BUILDING OUR COMMUNITY

## GENETIC ALLIANCE UK MEMBERS

Genetic Alliance UK drives improvement in diagnosis, treatment and care by speaking with a strong, united voice on behalf of people living with rare, genetic and undiagnosed conditions, their families, and the charities and support groups that advocate for them.

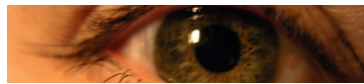
Genetic Alliance UK was delighted to welcome 15 new members in 2021/22. Membership of Genetic Alliance

UK is open to patient organisations and not-for-profit organisations associated with genetic conditions. This enables us to represent a wide range of people affected by genetic conditions and campaign for the broad issues which affect all of our members.

A full list of members can be found on page 61.



The Aortic Dissection Charitable Trust



Action on Gilbert's Syndrome



CSNK2A1 Foundation



Glut1 Deficiency UK



Great Ormond Street Children's Charity



Acrodysostosis Support & Research



FAST UK – Foundation for Angelman Syndrome Therapeutics



SCN8A UK & Ireland



ITP Support Association



WomenZone



Fop Friends (Fibrodysplasia Ossificans Progressiva)



CASK Research Foundation



ttpnetwork

Thrombotic Thrombocytopenic Purpura Network (TTP Network)



CureGRIN Foundation



SMC1A Foundation

# SUPPORTING OUR MEMBERS – BUILDING RARE RESILIENCE

**4 courses | 32 participants | 25 member organisations**

*‘This was a life changing experience for me for the positive and just what I needed.’*

Over the year we collaborated with RareMinds to run four courses of our Building Rare Resilience programme. The programme affords staff and volunteers at Genetic Alliance UK member organisations the opportunity to take part in 12 weekly sessions of group counselling. The sessions are run by a counsellor specialising in providing professional counselling and wellbeing resources to rare organisations’ staff and volunteers and aim to enable the individuals participating to build their emotional resilience and wellbeing.

Overall 32 individuals from 25 different member organisations attended across the 4 groups. All four groups have continued to meet regularly after their 12 weeks of official sessions ended, which is testament to the success of the programme.

## **Taking part in Building Rare Resilience – Phillippa’s Story**

Duchenne Family Support Group (DFSG) is a small charity (celebrating 35 years in 2022) that supports families who have children with the condition known as Duchenne Muscular Dystrophy. This is a rare genetic condition that mainly affects boys (as it is carried on their X chromosome) and is life-limiting. The muscles lack the protein known as dystrophin and so over time the boys’ muscles waste away. Usually by the age of seven to nine they will need a manual wheelchair, by mid-teens they will need an electric wheelchair and as they get older, they will need cardiac checks, help with all forms of personal care, including toileting and some may need a catheter fitted, ventilation and respiratory support. They may also need help with feeding and will need a PEG fitted.

In November 2019, just before the pandemic started, Phillippa lost her son Daniel who lived with Duchenne Muscular Dystrophy at age 27. Phillippa

works as a Development Officer at DFSG so she can help other families affected by the condition, and she decided to carry on even though it was a struggle as she coped with her grief. Although she misses Daniel dreadfully, he was always proud of the work that DFSG and Phillippa did to speak out on behalf of others.

When the Building Rare Resilience course was offered Phillippa decided to take part as she was not only struggling personally with her mental health, but she was also figuring out how to carry on working from home supporting the DFSG community and yet still be effective. She was exhausted from the continual Zoom meetings and social media messages, but since many families were struggling with their own journeys, she was hoping to talk to others in similar situations and to receive and give support going through the pandemic and beyond.

Phillippa felt the first meeting was a challenge, however, as soon as everyone got to know each other with the help of the facilitator and began sharing the things that were bothering them, everyone soon began to make new goals, relook their working practices. They were supported to continue to do their jobs, but much more effectively. As a result of these meetings, Phillippa’s small group became really connected to each other that even when the course finished, they continued to meet weekly and support each other.

*‘We have learnt so much from each other, shared top tips, helped each other when the going got tough, advised courses of action where necessary and been like a family to each other. We were extremely lucky to have built such a close network and we still to this day continue to meet weekly. I for one would hate this to stop.’ \*Phillippa*

## Community Check-ins

**38 sessions held | 244 attendees | 140 member organisations represented**

Our weekly virtual Community check-ins are the bedrock of our engagement work with our members allowing us to keep in regular dialogue about issues arising affecting our community. 38 sessions were held over the year (breaks were taken over the summer, Easter and Christmas holiday periods). Overall 244 different individuals attended the sessions, representing nearly 140 Genetic Alliance UK Member organisations.

Check-in topics included:

Good Diagnosis report  
[vimeo.com/689597864](https://vimeo.com/689597864)

England action plan for rare diseases  
[vimeo.com/687173960](https://vimeo.com/687173960)

Whole Genome Sequencing in the newborn  
(Genomics England)  
[vimeo.com/639586563](https://vimeo.com/639586563)

Barriers and facilitators for a rare disease diagnosis  
[vimeo.com/619040458](https://vimeo.com/619040458)

NHS Medicines Repurposing Programme

Running Awareness days

Covid-19 vaccines and vulnerable children (RCPCH)  
[vimeo.com/577207048](https://vimeo.com/577207048)

Genomics and the UK Rare Diseases framework

Succeeding in the digital world as a small charity  
[vimeo.com/694874196](https://vimeo.com/694874196)

# SWAN UK

SWAN UK (syndromes without a name) is the only specialist support network available in the UK for families of children and young adults affected by a syndrome without a name. We work with families of affected children and young adults aged 0–25, providing support and information in hospital, at home and in their local communities.

**3.7k members | 2.6k families | 6 virtual events | Dads Summit | Parent Rep workshop**

Over the reporting period we have welcomed a number of new SWAN UK members, bringing the total membership figure to 3,686.

The decision was made to run a hybrid programme of events for SWAN UK members with the continuation of online events to cater for those families who continued to shield their vulnerable children from Covid-19 as well as some face-to-face events for families who felt ready to meet up. Over the course of the year, six virtual events were held, including a SWAN UK Virtual Information Event that had over 100 people sign up to attend. Physical events were reintroduced in September once changes in Covid-19 restrictions permitted it and three physical events were held from September to the end of the reporting period. These events included a SWAN UK Dads Summit which was attended by 13 members and our SWAN UK Parent Rep Workshop which was attended by eight Parent Reps.

A SWAN UK Couples Counselling programme was launched in September in collaboration with RareMinds. Over 40 couples registered their interest in taking part, and during the reporting period 15 couples were able to take part on a first-come-first-served basis.

Additionally, 10 virtual Zoom catch-up sessions were run for SWAN UK dads and 11 rounds of virtual coffee meets were arranged for members.

During the reporting period we've started to rebuild our outreach programme, focussing on raising awareness of SWAN UK among other professionals working in the health and social care sectors. SWAN UK presentations have been given to a number of organisations, including:

- Institute of Health Visiting
- Clinical Genetics, University Hospitals Bristol and Weston NHS Foundation Trust
- Neurodisability Team, South Tyneside and Sunderland NHS Foundation Trust
- Lincoln Parent Carer Forum

## Undiagnosed Children's Day

Our awareness day, Undiagnosed Children's Day, took place on Friday 29 April 2022. As always this was an opportunity to share memories and experiences for our SWAN UK families. This year's day was special as we also celebrated SWAN UK's 10th birthday on 9 May.

# SWAN UK CYMRU

## **139 members | 98 families | 18 parents attended info event | 12 participants at pamper event**

SWAN UK membership in Wales continued to increase throughout the reporting period and in the first year of the project membership numbers in Wales rose at nearly double the rate of the rest of the UK. Our previous post-holder left the position of Engagement and Support Officer (SWAN UK – Cymru) at the end of September and after a successful round of recruitment Amanda Thomas started in the role at the beginning of January 2022.

Several successful online events were held including a UK wide virtual information day in April with a Wales specific breakout room. The event was well attended with 18 Welsh families and speakers attending the information session. In June a SWAN UK Cymru mum’s pamper event was held online with 12 sign ups. Five mums attended live and seven mums participated by watching the event recording. Since this, site visits have been made in preparation for the role out of a physical family event.

The project’s outreach has quickly gained momentum over the year and relationships have been forged with several key partners such as Contact Cymru, Tŷ Hafan Children’s Hospice and Same But Different. The SWAN UK Cymru project was also represented at meetings for the new Welsh Undiagnosed Research Hub and continued to be involved with the newly-launched SWAN Clinic, including feeding into the development of patient evaluation material. A presentation on SWAN UK Cymru was given to paediatricians in South Wales as part of a Paediatric Study Day that was held in January. SWAN UK – Cymru has also been represented at the Wales CPG, Rare Disease Day Reception at the Senedd and Wales Gene Park’s Genomics Cafe. These have all proved fruitful for networking opportunities, enabling the dissemination of information about the project through word of mouth.

Rare Resources Cymru (an early intervention information toolkit for families affected by rare or undiagnosed conditions) were translated into Welsh and designed ready for a year two roadshow.



SWAN UP  
without a

# BUILDING GREATER AWARENESS

## RARE DISEASE DAY 2022

**451.3k Twitter impressions | 12.3k Facebook reach | Website page sessions up 98% from Jan 2022**

*'I just wanted to say a big thank you to all of you for not only providing an amazing platform to amplify our voice on Rare Disease Day but for supporting us and rare diseases generally in everything you do.'*  
Rare Disease Day social media takeover participant

Rare Disease Day 2022 took place on Monday 28 February. It was celebrated in over 85 countries worldwide to raise awareness and generate change for 300 million people living with a rare condition, and their families and carers. Despite significant world events, #RareDiseaseDay2022 was trending on Twitter for most of the afternoon and evening. Engagement was high across all our platforms and participants in our social media take over slots reported similar increases in traffic to their channels.

*'Our Twitter engagement increased threefold (by 300%) on our Rare Disease Day Takeover Day.'*  
Social media takeover participant

### Rare Disease Day videos

**4 videos | Over 5k views**

Covid-19 has been extremely challenging for the UK's rare community with shattered support routines, reduced access to treatment and healthcare, and the increased isolation of shielding. The pandemic also shone a light on the increased health inequalities experienced by many marginalised groups in the UK, especially those from a black or minority ethnic community. Young people had their lives severely disrupted by schools and colleges closing. For many in the rare community, their rare condition is just one of many factors they are having to manage.

This Rare Disease Day we wanted to shine a light on these often unheard stories, while also demonstrating solidarity across the UK, Europe and Internationally.

### Rare repository

**Rare repository launched | Over 100 stories shared**

Over 100 people shared their story on our new rare repository to light up a virtual window for Rare Disease Day. You can read their stories by visiting [www.raredisease.org.uk/rdd2022/rare-repository/](http://www.raredisease.org.uk/rdd2022/rare-repository/).

### Shining a light on rare conditions

This year we partnered with ITN Productions Industry News to produce 'Shining a Light on Rare Conditions', a news-style programme raising awareness of people affected by rare, genetic and undiagnosed conditions. You can see the news programme at [geneticalliance.org.uk/gauk-news/news/shining-a-light-on-rare-conditions/](http://geneticalliance.org.uk/gauk-news/news/shining-a-light-on-rare-conditions/).



### Light up for rare

Private homes, public buildings and landmarks including the Department for Health and Social Care, the Kelpies and the Gateshead Millennium Bridge were lit up in the Rare Disease Day colours to express support for the day.

## Rare Disease Day parliamentary events

**3 events | 150 participants |**

**Hosted by Russell George MS | Liz Twist MP |  
Bob Doris MSP**

*'Thank you all, it's been a great session and to the amazing speakers.'*

Esther Florence, The Pituitary Foundation

Unlike in 2021, individual virtual receptions were hosted for the Welsh, and the Scottish parliament and Westminster so that discussion could focus on issues for rare conditions relating to each nation. The receptions focussed on the theme of diagnosis, hearing from a variety of speakers on their experience of the diagnostic odyssey for rare conditions. The events were attended by around 200 people in total.

The receptions had an array of speakers including people with rare conditions. We were also delighted to receive addresses from the respective health ministers: Maria Caulfield MP, Eluned Morgan MS and Maree Todd MSP who looked forward to the release of the rare disease action plan throughout the following year. Attendees appreciated the opportunity to network in a virtual capacity and talk to the speakers after they had presented.

Genetic Alliance UK presented the Good Diagnosis report on page 16 at each of the receptions which was well received by the rare condition community. The report collated and materialised the experiences around diagnosis for people with rare conditions in a format that could be shared with policy makers. There was a strong interest in the recommendation for a Good Diagnosis Rare Conditions Patient Charter.



# GOOD DIAGNOSIS REPORT

The lack of awareness about genetic, rare and undiagnosed conditions generally leads to slower referral, slower diagnosis, misdiagnoses and slower access to appropriate specialised care. Too often people living with the condition and their desperate families are left to research their own symptoms, or diagnosis, and this can lead to people finding unreliable, potentially alarming information which they have to digest without the support of a healthcare professional who understands the condition.

When an individual has a diagnosis of a rare condition that their principal healthcare professional does not know a lot about, they may continue to experience delays in being started on the correct care or treatment pathway, and they may experience delays in accessing appropriate services, medicines or research.

To coincide with Rare Disease Day 2022, Genetic Alliance UK launched, 'Good Diagnosis: Improving the experiences of diagnosis for people living with rare conditions'. Building on the findings of our Rare Resources (Scotland) and Rare Experience 2020 projects, we asked people to reflect on their experiences at three key stages of their diagnosis journey: their search for a diagnosis, receiving their diagnosis, and following diagnosis. The report identified the key principles of good diagnosis: a good diagnosis is timely and accurate, informed and supported, coordinated and collaborative, acknowledged and respected.

In the coming year we will work to implement the recommendations of the report:

- Increase awareness of rare conditions among healthcare professionals
- Ensure people with rare conditions have access to appropriate information and support throughout their diagnosis journey
- Develop a good diagnosis patient rights charter

Having to fight for the right care or treatment can be extremely challenging, particularly when

unwell. The fight can be harder when a person is unsure about what rights they have, or who can support them. It is vital that people living with rare conditions and their families are aware of what to expect from the diagnosis journey, aware of their rights and how they can challenge decisions.

The Good Diagnosis report recommends that a Rare Conditions Good Diagnosis Patient Rights Charter should be developed to clearly communicate the standard of care people with rare conditions should expect to receive. We will be working closely with individuals, families and member organisations to listen to their views on what it should look like.

You can read the Good Diagnosis Report at [geneticalliance.org.uk/gauk-news/news/good-diagnosis](https://geneticalliance.org.uk/gauk-news/news/good-diagnosis)



# GOOD DIAGNOSIS INFOGRAPHIC



## Communications

**Twitter reach 254k | Facebook reach 153.5k | 1,200 new Instagram followers**

We have made significant strides in utilising our different platforms in an increasingly strategic way, curating content so that we are making the most of what each platform has to offer and engaging different audiences.

Over the last year we have maintained a strong presence on social media and had a high level of engagement across our channels. To illustrate this, the combined profile visits for all of our Twitter accounts was 254,381. Our combined Facebook page reach for all the channels was 153,515 and new followers across our Instagram accounts was 1,200. In addition, at the end of March 2022 we had 1,596 LinkedIn followers.

## Social media takeovers

We regularly arrange for our social media channels to be ‘taken over’ by people with rare conditions, their families and the member organisations that support them. This helps our smaller member organisations and individuals living with the rarest conditions to increase their social media reach and gain new followers by communicating directly with the people who are following Genetic Alliance UK, Rare Disease UK and SWAN UK.

*‘Thanks again for this wonderful opportunity to raise awareness. We are so grateful to have your support ....’* Marfan Trust

In addition to Rare Disease Day and Undiagnosed Children’s Day, we have been working closely with our members to highlight the work that they do to support people with genetic, rare and undiagnosed conditions.

*‘Thank you so much for having us, I think it was a great thing to do to raise awareness of Genetics and what we do ...’*

## Website

**882.4K website views | 20 Genetic Alliance UK member articles | 15 rare stories**

Our website traffic has increased significantly demonstrating our high-quality content and promotion through our social media channels. Our websites received a combined 882,421 page views. We have collaborated closely with members and published more than 20 articles raising awareness of the conditions that they support as well as publishing 15 stories on Rare Disease UK highlighting the impact that rare conditions have on people and their families.



# DRIVING PROGRESS

## ALL PARTY PARLIAMENTARY GROUP ON RARE, GENETIC AND UNDIAGNOSED CONDITIONS (ENGLAND)

Genetic Alliance UK provides the secretariat to the APPG for Rare, Genetic and Undiagnosed conditions, which is chaired by Liz Twist MP. Thanks to Liz's excellent chairing and commitment this year, we brought some key issues to the attention of parliamentarians.

### APPG: Access to medicines (England)

**April 2021 | 14 parliamentarians | 4 speakers | NICE and NHS England attendance**

*'I thought that was a very good meeting today with signs that progress is being made'*

14 parliamentarians including the Minister in charge of rare diseases, Lord Bethell, joined the meeting.

**Guest speakers included: Kye Gbangbola (Sickle Cell Society), Kate Learoyd (National Society for Phenylketonuria), Emily Crossley (Duchenne UK), Jess Hobart (The UK Mastocytosis Support Group) and Roanna Maharaj (UK Thalassaemia Society).**

Speakers highlighted the many challenges they faced in accessing rare disease medicines.

Also in attendance was Meindert Boysen, Deputy Chief Executive and Director of the Centre for Health Technology Evaluation at NICE and Nina Pinwill, Head of Commercial Operations, Commercial Medicines Directorate at NHS England and NHS Improvement.

Discussions considered health inequality and the need for improvements in educating healthcare professionals. Attendees questioned when decision making bodies, such as NICE committees, would become more representative of the population and who should be responsible for ensuring data is collected in a way that is suitable for decision makers as the burden is often on people affected by rare conditions. Watch the meeting [vimeo.com/542729454](https://vimeo.com/542729454)

*'Thank you for inviting me to the Rare Disease APPG. It was interesting and very valuable.'*

Head of Office for Mr Andrew Lewer MBE MP

### Newborn screening (England)

**June 2021 | 8 parliamentarians | 7 speakers | 3 key policy asks agreed**

In June 2021, the APPG held a meeting on newborn screening. Eight parliamentarians and their representatives were in attendance to hear from a number of guest speakers, including: Professor Simon Heales (Great Ormond Street Hospital), Professor Laurent Servais (UK Newborn Screening Alliance & Muscular Dystrophy UK Oxford Neuromuscular Centre), Dr Will Evans (Niemann-Pick UK), Amanda Mortensen (Batten Disease Family Association), Karen Harrison (Alex – The Leukodystrophy Charity), Mandy Sanderson (Max Appeal) and Georgina Morton (ArchAngel MLD Trust).

Attendees agreed on the need for:

1. The formation of a dedicated team of newborn screening experts to solely evaluate conditions to be added to the newborn screening programme.
2. The establishment of a streamlined evidence review process for evaluation of conditions to be added to the UK newborn screening programme.
3. A timeline to ensure appropriate efficiency and accountability for this process.

Attendees also called for regular, meaningful and transparent engagement with stakeholders. Watch the meeting <https://vimeo.com/561340806>.

## **APPG: Parliamentary Outreach (England)**

**October 2021: 6 parliamentarians | 2 speakers | Update meeting – NICE Methods Review | newborn screening landscape | UK Rare Disease Framework**

The APPG held a short meeting in October 2021 to provide an update on the NICE Methods Review, the newborn screening landscape and the UK Rare Diseases Framework. Six MPs and their representatives attended the meeting to hear from guest speakers including: Jess Hobart (The UK Mastocytosis Support Group (Masto UK)) and Karen Harrison (Alex – The Leukodystrophy Charity).

The MPs in attendance asked for more information on the differences across the nations in relation to the UK Rare Diseases Framework.

For this meeting, we launched the DoGooder tool which can be used by people in the rare community to contact their local MP, asking them to express interest in the APPG and broader activities related to rare conditions. You can see the DoGooder tool in action at [geneticalliance.org.uk/gauk-news/news/rareappg-get-mps-to-support-people-living-with-rare-genetic-and-undiagnosed-conditions/](https://geneticalliance.org.uk/gauk-news/news/rareappg-get-mps-to-support-people-living-with-rare-genetic-and-undiagnosed-conditions/). There are now also tools that can be used in the Welsh, Scottish and Northern Irish parliaments which altogether have been used over 200 times. This tool has helped the cross party groups to reach a wider

group of members of parliaments and engage the rare community in our parliamentary activity.

## **APPG: The UK Rare Diseases Framework (England)**

**December 2021 | 7 parliamentarians | 3 speakers | hosted in conjunction with APPG for life sciences**

In December 2021 the APPG held a meeting in conjunction with the APPG for Life Sciences, looking into the UK Rare Diseases Framework. Seven MPs, Lords and their representatives joined to hear from a number of speakers from both APPGs including: Kerry Leeson Beavers, (Alstrom Syndrome UK), Victoria Barrett, (The Association of the British Pharmaceutical Industry); and Jon Neal, (Takeda).

The attendees heard from a variety of stakeholders that sat on the bodies that were working on the development of the England Action Plan.

# POLICY ENGAGEMENT

## 4 'Policy, Policy, Policy' community check-ins | 2 consultation webinars

### Community check-ins

- 4 x 'Policy, Policy, Policy!' sessions hosted.
- Public affairs activities and the Rally for Rare campaign
- Our work with the Human Fertilisation and Embryology Authority (HFEA) on preimplantation genetic testing for monogenic disorders (PGT-M)
- Patient and public involvement in decision making
- UK Rare Diseases Framework and nation specific action plans
- Relevant policy consultations and other opportunities for involvement

### Consultation webinars

- Innovative Medicines Fund (IMF) consultation  
*'Thank you ... very informative and objective, but most of all helpful.'*  
IMF consultation webinar participant
- Webinar hosted: NICE Methods and Processes review

## PGT-M statements for Human Fertilisation and Embryology Authority

### 50 statements submitted | 46 licences approved

HFEA feedback: Genetic Alliance UK statements made the condition 'come alive' and had a 'direct impact' on the committee's decision.

50 statements on preimplantation genetic testing for monogenic disorders (PGT-M) were provided to the Human Fertilisation and Embryology Authority (HFEA). Genetic Alliance UK reached out to the community to put together statements that portray the patient experience of living with a specific genetic condition. These statements are used as evidence when a committee at the HFEA makes the decision on whether to grant a PGT-M license for this condition, enabling families to have the choice of having a biological child without passing on the genetic condition.

# PATIENT EMPOWERMENT GROUP (PEG)

**14 members | 9 meetings |  
Key recommendations report produced for  
UK Rare Diseases Framework**

The Patient Empowerment Group (PEG) is a collaborative forum which enables patient representatives with an interest in rare and genetic conditions to come together to support one another in their efforts to represent people living with rare, genetic and undiagnosed conditions. PEG members from across the UK play a key role in advising on the development of the action plans which will implement the UK Rare Diseases Framework

Nine meetings were held during 2021/22, five of which reviewed the four priorities and the underpinning themes outlined in the UK Rare Diseases Framework. The meetings highlighted activity already happening and identified specific areas of interest and concern for the rare condition community under each of the priorities. A report was produced to outline key recommendations taken from these meetings which were fed into the delivery groups that were developing each nation's action plan.

Subsequent meetings focussed on scrutinising the implementation of the UK Rare Diseases Framework and ensuring that the voice of the rare condition community was effectively represented in the action plans. Members sitting on the delivery groups brought points of interest to the PEG meetings and received opinions from the rare condition community so that they could feed in a more representative voice to the development of the action plan. It also provided a space for cross-border collaboration.

The PEG members also acted as a sounding board for policy work at Genetic Alliance UK, contributing their insight on a wide variety of issues including the Down Syndrome Act, the Good Diagnosis report, the Rare Disease Day parliamentary receptions, and best practice when recruiting to roles for people with experience of living with rare conditions.

# MAKING OUR MEMBERS' VOICES HEARD

Genetic Alliance UK staff sit on numerous committees, boards and steering groups to represent and champion the needs of the UK's genetic, rare and undiagnosed community.

- Breaking Down Barriers Advisory Board
- British Society for Gene and Cell Therapy Stakeholder Panel meeting
- British Society for Genetic Medicine Consensus Guidance development group for Pre-implantation Genetic Diagnosis (PGD)/ Pre-natal Diagnosis and (PND) for Cancer Susceptibility Genes
- Charity Medicines and Access Coalition
- Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland Expert Advisory Panel (Scotland)
- Decipher Project Data Access Committee
- Delivering genomic sequencing in clinical practice: a patient-centred evaluation of the new NHS Genomic Medicine Service – Project Advisory Team
- Department of Health and Social Care UK and Sweden roundtable
- EURORDIS Council of National Alliances
- EURORDIS Membership Meeting 2021
- EXPRESS Study PPI group
- Genetic Counsellor Registration Board
- Genetics Laboratory Management Review Group (Scotland)
- Genomics England Newborns Ethics Working Group
- Genomics England Public dialogue on whole genome sequencing for newborn screening – oversight group
- Genomics Leadership Group (Scotland)
- Genomics Partnership Wales Programme Board
- Manchester University MSc in Advanced Therapy Medicinal Products
- National Genomics Board
- National Institute Health Research Advanced Therapy Medicinal Product Coordinating Group
- National Patient, Public and Professional Involvement Group (Scotland)
- Newborn Screening Collaborative
- NHS England – Accelerated Access Collaborative Advanced Therapy Medicinal Product Patient and Public Involvement and Engagement Working Group
- NHS England – Genomics People and Communities Forum
- NHS England – Genomics Programme Board
- NHS England – Patient and Public Voice Assurance Group
- NHS England – Preimplantation Genetic Diagnosis Commissioning Policy Development Group
- NHS England – Specialised Commissioning Stakeholder Forum
- NICE Guideline Committee – Children and young people with disabilities and severe complex needs
- NICE Methods review – working group and task and finish groups
- Office for Rare Conditions (Glasgow) Steering Group
- Preimplantation Genetic Testing Expert Panel (Scotland)
- Public Involvement Network Advisory Group Meeting (Scottish Medicines Consortium)
- Public Policy Projects Rare Disease Coalition
- Responding to genetic risk associated with customary consanguineous marriage
- Scotland Rare Disease Implementation Board
- Screen4Care Patient Advisory Board
- Solve RD Community Engagement Task Force – Steering Group Meeting
- UK Rare Disease Framework Board
- UK Rare Disease Stakeholder Forum
- Wales Rare Disease Implementation Group

# WALES

## Preparing for Wales Rare Disease Action Plan

Our key priority is for all the Action Plans to be informed by the views of people living with rare conditions. In Wales we have played a key role in collecting those view points. We collaborated with Genomic Partnership Wales and the Wales Rare Disease Implementation Group to deliver two consultative meetings in November, attended by 47 people between them. These were shared directly with the authors of the Welsh Rare Disease Action Plan.

## Working with Wales Gene Park

Working with Wales Gene Park and Genomics Partnership Wales, Genetic Alliance UK continues to hold regular virtual engagement events such as the Genomics Cafes. We now host specific cafe's to engage with younger people (aged 16-25) and spin out cafes such as one held in collaboration with Friends of Cymru Sickle Cell & Thalassaemia, focussing on inherited haematological conditions.

## Policy engagement in Wales

HFEA feedback: Genetic Alliance UK statements made the condition 'come alive' and had a 'direct impact' on the committee's decision.

With Emma Hughes, our team member based in Wales Gene Park, on maternity leave, for the second half of the year we split her duties between the Gene Park and our team this year, with our team maintaining connections with the Rare Disease Implementation Group and Genomics Partnership Wales, and providing the secretariat to the Cross Party Group on Rare, Genetic and Undiagnosed Conditions.

## Senedd meeting Jan 2022 |

Russell George MS chaired a meeting for Members of the Senedd in January 2022 to reintroduce the topic of rare conditions following the elections. Four MS and their representatives attended the meeting where we broached the topic of diagnosis and care coordination. The attendees

heard from an array of speakers including: Martin Williams, member of SWAN UK; Michelle Conway, Rare Disease Nurse Network; Amy Simpson, the CoOrdinated Care of Rare Diseases (CONCORD) study; and Dr Graham Shortland, SWAN Clinic pilot.

Discussion focussed on next steps for the SWAN Clinic pilot and how it will contribute to improving diagnosis for people with undiagnosed conditions, especially how care would be handled once a diagnosis was received.

# RALLY FOR RARE

## Candidate pledges doubled since 2016 campaign | 120 in Scotland | 84 in Wales

Between 6 April and 6 May 2021, Genetic Alliance UK ran a pre-election campaign ahead of the Scottish and Welsh elections. We asked our members and supporters of our projects, Rare Disease UK and SWAN UK, to contact their local prospective parliamentary candidates (those standing for election to become MSPs and MSs) to encourage them to pledge their support for people affected by rare, genetic and undiagnosed conditions.

Rally for Rare has helped to raise awareness of rare, genetic and undiagnosed conditions, galvanise our relationships with parliamentarians in the devolved parliaments, and support our efforts to re-establish Cross Party Groups (CPGs) in each nation. The CPGs have been vital in ensuring the voices of people living with rare, genetic and undiagnosed conditions are represented in parliament. The campaign also facilitated the opportunity for our members and supporters to establish closer links with their local representatives.



# SCOTLAND

## Access to Medicines (Scotland)

### Stakeholder consultation | Medicine matters magazine produced

In Scotland, we have been working on the Why Medicines Matter project. In collaboration with Michelle Conway from CRD Consulting (who has supported the project as a Policy Expert Volunteer), we have undertaken a programme of engagement activities to explore how access to medicines in Scotland can improve. The project focused on consultation with three key stakeholder groups; support organisations, clinicians and industry. A summary report of our findings will be shared with the Scottish Government's Rare Disease Team. For this project, it was also important that participants could, in their own words, share why medicines matter to them. To facilitate this we have created a supplementary Why Medicines Matter magazine featuring articles and contributions from key stakeholders which we will use over the course of the next 12 months as part of a social media campaign. You can find Why Medicines Matter at [geneticalliance.org.uk/gauk-news/news/why-medicines-matter/](https://geneticalliance.org.uk/gauk-news/news/why-medicines-matter/).

## UK Rare Diseases Framework (Scotland)

We have been working closely with the Scottish Government's Rare Diseases Team to deliver a programme of involvement events for people living with rare conditions in Scotland. Our Policy and Engagement Manager for Scotland has chaired the Scottish Government's Rare Disease Patient Voices Advisory Group and is also a member of the Rare Disease Implementation Board and Short Life Working Group on Care Coordination. The Rare Disease Action Plan for Scotland is expected in summer 2022.

Genetic Alliance UK are represented on the UK Rare Diseases Stakeholder Forum by Natalie Frankish, Policy and Engagement Manager for Scotland.

# CROSS PARTY GROUP (CPG) ON RARE, GENETIC AND UNDIAGNOSED CONDITIONS (SCOTLAND)

Following the 2021 Scottish Parliamentary elections, we were quickly able to re-establish the CPG on Rare, Genetic and Undiagnosed Conditions. The group continues to act as a forum for people with lived experience, support groups, clinicians, policy members and elected officials to come together and explore issues relevant to our community. There have been three meetings of the CPG:

## CPG: The four priorities of the UK Rare Diseases Framework.

### June 2021 | 31 Participants including 2 Members of the Scottish Parliament |

In June we heard from Professor Zosia Miedzybrodzka about the work being undertaken to increase Scotland's genetic testing capabilities, Dr Martina Rodie from Office for Rare Conditions in Glasgow spoke about the need to increase awareness of rare conditions amongst healthcare professionals in NHS Scotland and Dr Catherine McWilliam described the work being undertaken by the Scottish Muscle Network to improve coordination of care and raised the issue of the need to improve the newborn screening programme in Scotland so that people with rare conditions could benefit from treatments available in Scotland. This meeting highlighted the issue of newborn screening for Spinal Muscular Atrophy, which would become a focus for the CPGs work.

## Newborn screening.

### October 2021 | 29 Participants | 2 parliamentarians

We wrote a letter to the Cabinet Secretary for Health and Social Care to ask for further details of work being undertaken to develop Scotland's Action Plan and to ask for details on Scotland's Newborn Screening Programme, specifically, how decisions on which conditions were included were made. In November we presented our

community's view on this topic, followed by Professor Tom Gillingwater and Dr Catherine McWilliam detailed the complex case regarding spinal muscular atrophy in Scotland. The discussion highlighted that it was unclear what role the Scottish Screening Committee had in relation to newborn screening and it was decided that further information should be sought.

## CPG: Access to medicines (Scotland).

### January 2022 | 41 Participants | 4 Parliamentarians | Presentations on Why Medicines Matter project |

In January, the meeting's theme was priority four of the UK Rare Diseases Framework, improving access to services, treatment and drugs. A presentation was delivered by Michelle Conway (Director of CRD Consulting and Policy Expert Volunteer for Genetic Alliance UK) on the initial findings of the Why Medicines Matter project. We also heard testimony from Kate Learoyd from the National Society for Phenylketonuria (NSPKU) and Michaela Regan from Muscular Dystrophy UK, which highlighted the importance of access to medicines for their communities.

# RARE RESOURCES

## Rare Resources Scotland

Rare Resources Scotland is a project designed to address information and resource gaps for people living with rare, genetic and undiagnosed conditions in Scotland. Through consultation with members of our community we have identified the information needs of our community and developed a series of information toolkits and guides.

The guides include a toolkit for families with a child or young adult with a rare, genetic or undiagnosed condition, a guide for adults living with a rare condition and a guide about rare conditions for healthcare professionals working in Scotland.

Throughout 2021/22 we have delivered information sessions to the community as part of our Rare Resources offering – this has included sessions on mental health support from Breathing Space and information on financial support for families through Family Fund.

A Rare Resources Information website has been designed to present and disseminate the Rare Resources Scotland toolkit. The webpage has capacity to be expanded to include further resources and can be adapted to include resources from other parts of the UK. You can find out more at [geneticalliance.org.uk/information/living-with-a-genetic-condition/rare-resources/](https://geneticalliance.org.uk/information/living-with-a-genetic-condition/rare-resources/).

Discussions are underway to include Rare Resources on NHS Inform, NHS Scotland's health information online resource.

# THE VIRTUAL INVOLVEMENT PANEL (SCOTLAND)

## Scotland | 80 panel members

In Scotland we have developed a Virtual Involvement Panel for people living with, or caring for someone living with genetic, rare or undiagnosed conditions. The 'VIP' will be at the heart of our work in Scotland and our panellists (our VIPs) will be regularly invited to share their views and experiences to ensure future policy and service planning for rare, genetic and undiagnosed conditions in Scotland meets their needs. VIPs receive regular communication about developments in health and social care services, access to our programme of digital events, opportunities to get involved in our work and invitations to take part in surveys and consultation events to shape policy and services in Scotland.

# RESEARCH

## Dissemination of CONCORD and mental health findings | one new member group project | two new academic projects

An important aim of our research activities is to support the development of policy by providing reliable and relevant evidence. This year saw a concerted effort to feed the findings of our major study on care coordination (CONCORD) into the national action plans designed to deliver on the commitments of the UK Rare Diseases Framework. Our policy team and members of the study team were able to present and discuss the CONCORD data in several forums and the project is quoted multiple times in the England plan – the first to be published (February 2022). Similarly our 2018 mental health study continues to inform policy work – the Good Diagnosis report uses its findings and those from CONCORD.

We also continue to draw on external scientific studies to support our work. Through a partnership with UCL we were part of a systematic review of evidence around the barriers and facilitators to diagnosis of rare conditions, and we carried out a scoping review of studies about remote (phone/video) healthcare appointments as it became clear that this mode of operation would continue beyond the pandemic. This work is feeding into our policy and further research plans.

### Member group research support

We are keen to continue offering research support to our member groups – this can take the form of advice and review, or performing research on a member group's behalf. With Alex TLC we started a new project in March 2022, and began discussions with Ataxia UK for a follow up to their 2020 phase of research.

### Mental health support – evaluation

The psychotherapeutic group support that was put in place for our members during the pandemic, through partnering with Rare Minds UK, was extremely helpful according to informal feedback from participants. To properly assess the intervention and build a case for continued

support we worked with Manchester Metropolitan University and began an indepth interview study which will report later in 2022.

### Evaluation of Rapid Genome Sequencing (rGS) for Critically Ill Children

We are partners in this new NIHR-funded study which is led by researchers at Great Ormond Street Hospital. It will evaluate the introduction of rapid genome sequencing for critically ill children who are in hospital and who urgently need a diagnosis. As with previous projects such as CONCORD, Genetic Alliance UK is in the valuable position of being able to play an active part in the research and at the same time ensure that the opinions of people affected by rare conditions are at the heart of the design and delivery of the study. Since the work began in November 2021 we have developed a survey for parents/carers and established a highly engaged 'public and patient involvement' (PPI) advisory group consisting of parents/carers with a range of relevant experience.

### Papers published from research collaborations

Walton H, Simpson A, Ramsay A.I.G. Hunter A, Jones J, Ng PL, Leeson-Beevers K, Bloom L, Kai J, Kokocinska M, Sutcliffe AG, Morris S, Fulop N . Development of models of care coordination for rare conditions: a qualitative study. *Orphanet Journal of Rare Disease* 17, 49 (2022).

Sanderson SC, Lewis C, Hill M, Peter M, McEntagart M, Gale D, Morris H, Moosajee M, Searle B, Hunter A, Patch C, Chitty LS. Decision-making, attitudes, and understanding among patients and relatives invited to undergo genome sequencing in the 100,000 Genomes Project: A multisite survey study. *Genetics in Medicine* 24, 61 (2021).

Peter M, Hammond J, Sanderson SC, Gurasashvili J, Hunter A, Searle B, Patch C, Chitty LS, Hill M, Lewis C. Participant experiences of genome sequencing for rare diseases in the 100,000 Genomes Project: a mixed methods study. *Eur J Hum Genet* 30, 604–610 (2022).

# RAPID GENOME SEQUENCING INFOGRAPHIC

## Who can complete the survey?



You can complete the survey if you are the parent or carer of a child with a rare, genetic or undiagnosed condition. You can also complete the survey if you are a bereaved parent or carer of a child who had a genetic, rare or undiagnosed condition. You must be 18 or over and live in the UK.

## Who is organising and funding the survey?

The survey is being carried out by researchers and advisors at Great Ormond Street Hospital, Genetic Alliance UK and Breaking Down Barriers. The survey is funded by the National Institute for Health Research (NIHR202725).



## Do I have to take part?

No. It is up to you to decide whether or not to complete the survey. You are free to skip any of the questions in the survey that you would prefer not to answer. You are free to stop filling in the survey at any time before you submit the completed survey. It will not be possible to withdraw your response once you have completed and submitted your answers.

## Will my taking part in the survey be kept confidential?



Yes, all information about you will be kept confidential. Some of the questions in the survey will ask you to share your thoughts or provide more detail. It may be helpful for us to use your quotes in an academic publication, conference presentation or report. Quotes will be anonymous – this means we will do what we can to protect your identity so that people reading the quotes will not know who they are from. For example, we will not name people or include the name of any genetic conditions.

## What if I find the survey upsetting?

It may be upsetting for you to think about your own experiences with your child. The survey questions are very general and you will not be asked to share specific details about your child and experiences. You can stop at any time and return to the survey later. Because your previous responses will have been saved, you will be able to continue the survey where you left it. If you need support, you can contact the research team and we can put you in touch with someone from your clinical team if you feel this would be helpful, or provide you with details of a patient support group.



## Can I find out the results of the survey?

If you wish, you can add your email address to the last page of the survey and we will contact you at the end of the study to send you a short summary of the findings. Your email address will be kept separately from your survey answers.

## Who can I contact if I have any questions about the survey?

You can contact the researchers Melissa Hill (Great Ormond Street Hospital) or Amy Hunter (Genetic Alliance UK).

Melissa Hill: RGSevaluation@gosh.nhs.uk/ 020 7405 9200 (ext. 4944)

Amy Hunter: amy.hunter@geneticalliance.org.uk

## Download participant information sheet

For more detailed information on participating in the survey, including how we protect your data, please read the participant information sheet by clicking on the link below.

## Survey for parents and carers of children affected by rare, genetic or undiagnosed conditions



Do you have experience of caring for a child with a rare, genetic or undiagnosed condition?

Can you help to shape our research study by completing a survey?

We would like you to share your views! Everyone who answers the survey will have different views and ideas; they are all important.

## What is the survey about?

We are starting a research study to look at how a test called, “rapid exome sequencing”, has been offered in the NHS since October 2019. The test is being offered to babies and children who are seriously ill. Those who are offered a test are usually being cared for in a newborn or paediatric intensive care unit. The test can find out if there is a genetic condition which is making them unwell.

This survey is the first step in our two year research study. We are asking you to complete this survey to help us to work out the most important things to look at in our research. It will also help us decide what information would be most helpful to share at the end of the study.

## How long will it take?



The survey will take 15-20 minutes to complete. You can complete the survey online, over the phone or on paper. If you would prefer to complete the survey over the phone with a member of the research team, request a paper copy of the survey, or take part in a different language, please get in touch with the research team.

## What will the survey ask me to do?

There are three parts to the survey:

Part 1	Part 2	Part 3
<b>Read or watch a short summary of the test</b>	<b>Read or watch a short summary explaining our research</b>	<b>Tell us a little about you</b>
We will ask you to read or watch a short summary of the test and when it is used. Then there will be some questions asking what you think about the test.	We will ask you to learn about our planned research to evaluate the test. Then there will be some questions about our research.	We will ask some questions about you, such as your age, ethnicity and previous experience of genetic testing.

# BUILDING OUR ORGANISATION

In 2021/22 we have focused on being responsive to the needs of the diverse community that we serve – everyone affected by a genetic, rare or undiagnosed condition. As the UK’s largest alliance of rare and genetic organisations, we have a responsibility to ensure that all voices are heard.

Internally we have carried out a diversity and inclusion review of our internal and external working practices and are committed to taking action to make our organisation fully representative of the community we serve. We are conscious that this is just the start of our journey.

Externally, we have focused on strengthening existing relationships with our members and key stakeholders while also forging new and mending lapsed ones. We have strived to give our members the best possible platform to achieve their aims, including by introducing new member benefits to amplify their voices.

Following the publication of the UK Rare Diseases Framework, we put significant resources into ensuring that there are as many voices of people living with genetic, rare and undiagnosed conditions as possible feeding into the development of the four nations’ implementation plans. We did this by empowering our membership to take up formal representative roles, supported by our team where needed, and empowering our broadest networks to feed into the process. We supported all of our representatives and provided a forum for them to exchange information and support each other.

We carried the thread of inclusion through to our work on the UK Rare Diseases Framework to make sure that the voice of our community in this process is diverse and representative. Where we were concerned that there were not enough diverse voices round the table, in terms of both ethnicity and lived experience, we acted as critical friend and raised our concerns proactively with ministers in the UK governments.

We continued to utilise a hybrid approach to working this year, with some staff members co-located in a shared workspace while the majority of the team worked from home. We worked hard to bring the team together virtually and face-to-face where possible to maintain the sense of team spirit that was a key element of our previous office-based environment.

# THE COMING YEAR

2022/23 will be an important year for Genetic Alliance UK, as our five-year strategy for 2019-2023 draws to a close and we look to the future. We will evaluate the outcomes of this strategy to learn what has worked well, what has worked less well, and what we would like to do differently in future.

We were joined in July 2022 by our new Chief Executive Louise Fish, who previously led the Tuberous Sclerosis Association, one of the amazing rare disease charities that make up Genetic Alliance UK's membership. Louise's priority will be to lead the development of a new five-year strategy for Genetic Alliance UK setting out how we will continue to drive improvements in treatment and care by speaking with a strong, united voice on behalf of people living with rare, genetic and undiagnosed conditions, their families and the member groups that advocate for them.

Our strategy development will kick off in Autumn 2022 with a listening exercise that puts the individuals, families and organisations we support at its heart. We will shape our five-year strategy through a consultative process with members, potential partners and stakeholders in Spring 2023, so that it is ready for approval by the Genetic Alliance UK Board in Autumn 2023.

We will continue on our journey to make Genetic Alliance UK fully representative of the community we serve by implementing the recommendations resulting from the diversity and inclusion review of our internal and external working practices.

We anticipate that the UK fundraising environment will continue to be challenging for the next few years, due to the global and national impact of the war in Ukraine, rising inflation, and the increasing costs of living. In 2022/23 we will implement the recommendations set out in our recently developed fundraising strategy which sets out how we will diversify and grow our income across corporate partnerships, trusts and foundations, and community fundraising.

In the coming year we will also challenge ourselves to work even more efficiently as a charity, making sure we can invest as much of our time and resources as possible in delivering for our beneficiaries. We will streamline our internal processes and procedures, retender external services to make sure we get good value for money, and investigate the potential to save on office costs by sharing space with one of our member charities.

Most importantly, we will continue to drive the changes that are needed to improve the lives of people living with rare, genetic and undiagnosed conditions and their families. The UK Rare Diseases Framework and the four nations' implementation plans represent a unique opportunity to deliver positive change. We will continue to ensure that the voices of the individuals, families and organisations we support are heard loud and clear in the development of updated implementation plans for each nation in 2022/23. Our goal is to drive demonstrable improvements for our community across diagnosis, awareness of rare conditions, coordination of care, and access to specialist care, treatments and drugs. Working hand-in-hand with the incredible individuals, families and member organisations that we represent, we are stronger together and determined to succeed.

# TREASURER'S LETTER AND FINANCIAL REVIEW

31 March 2022

Thank you to all our members and funders. You have ensured that the work outlined in this report could continue at such a challenging time for the people we support.

## Review of the financial position

### Income

The results for the year are set out in the statement of financial activities on page 42. The total income for year was £713,568 (£939,440 in 2021).

This is a substantial decrease across both restricted and unrestricted income and highlights the continuing challenging fundraising environment. It also should be noted that the previous year saw exceptional support from our supporters in the first year of the pandemic and access to the Government's Job Retention Scheme throughout that period.

A detailed breakdown of income across the two years is included in Note 2 of the Financial Statements.

### Expenditure

Total expenditure for the year was £762,424 (£808,907 in 2021).

The decrease in the spending is proportionately smaller than the fall in income, which reflects the focus on the delivery of projects in support of our charitable activities.

The continuing cost control measures taken by the organisation and the focus on delivering impact have led to a substantial fall in support costs during the period as shown in Note 5.

### Surplus/Deficit

Our final financial position for the year across all funds is a deficit of £48,856 (surplus of £130,533 in 2021). This total is driven by modest deficits on both restricted and unrestricted funds.

This reflects the exceptional factors that contributed to the surplus in 2021 and the continuing challenging fundraising environment.

## Reserves Policy

Total reserves at the end of the financial year are £151,008 (£199,864 in 2021).

This is made up of restricted reserves of £16,351 (£39,134 in 2021) and unrestricted reserves of £134,657 (£160,730 in 2021).

The decrease in restricted reserves is due to slightly higher spending than income on specific projects as detailed in Note 19.

The decrease in unrestricted reserves is due to the inability to maintain unrestricted income levels at prior year levels.

The Trustees have set a target in the medium term to hold unrestricted reserves that equate to approximately 6 months of unrestricted expenditure. Our current level of reserves has decreased over the year and is now approximately 3.5 months by this measure.

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

## Conclusion

The financial year ended 31 March 2022 was a challenging one for Genetic Alliance UK from an operational and financial perspective, as the second full year of the Covid-19 pandemic.

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

Genetic Alliance UK starts the period with solid financial foundations. We are pleased that the auditors have endorsed the view that GAUK remains a going concern and we will work to ensure that it continues to be there for all those who need.



**D A Ramsden**

Treasurer, Board of Trustees

# STRUCTURE, GOVERNANCE AND MANAGEMENT

## Constitution

Genetic Alliance UK is the trading name for Genetic Alliance UK Ltd, a registered charity and a company limited by guarantee, incorporated on 6 April 2006 and governed by its Memorandum and Articles of Association.

## Appointment and training of Trustees

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

## Governance and organisational management

Trustees met four times in the year ending 31 March 2022, where they reviewed the charity's performance and determined and approved operating plans and budget. Trustees delegate certain powers in connection with the charity's management, remuneration (related to responsibility and market comparisons) and administration to the Finance and Governance (F&G) committee which met four times in the year. The F&G committee provides detailed oversight and advice to the Board of Trustees in relation to financial management, financial viability, risk management and governance. The F&G committee has a minimum of three Trustee members, appointed from and by the Board of Trustees that includes the Treasurer (Chair of the Committee), Chair of Genetic Alliance UK and the Deputy Chair. The Chief Executive and Directors of Genetic Alliance UK are ex officio.

## Risk management

Trustees have considered the major risks to which the charity is exposed and have established procedures including a risk register to identify and manage those risks. All risks are reviewed at each meeting of the Board of Trustees and by the F&G committee.

## Fundraising

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

# REFERENCE AND ADMINISTRATIVE DETAIL

## Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined in the Companies Act 2006.

## Registered company number

05772999

## Registered charity numbers

1114195 & SC039299

## Registered office

Creative Works, 7 Blackhorse Lane, London, E17 6DS

## Trustees

Ms Sondra Butterworth (resigned July 2021)

Ms Gloria Clark

Ms Phillippa Farrant

Ms Sara Hunt

Dr Celine Lewis

Mr Neil McClements

Mrs Sue Millman

Mrs Elizabeth Porterfield

Mr David Ramsden

Dr Susan Walsh

Mrs Julie Wooton

Dr Sarah Wynn

## Board observer

Robin Nott

## Chief Executive Officer

During the period of this report: Lauren Roberts and Nick Meade (appointed as Joint Interim Chief Executives April 2021)

Currently: Louise Fish (joined July 2022)

## Management team

Dr Amy Hunter, Nick Meade, Lauren Roberts (left July 2022)

## Auditors

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

## Management accountant

Fiona Bevan Financial Management

## Bankers

CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Mailing, 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](http://geneticalliance.org.uk)

## Facebook

GeneticAllianceUK

## Twitter

GeneticAll\_UK

## Instagram

GeneticAllianceUK

## LinkedIn

Genetic Alliance UK

# TRUSTEE RESPONSIBILITY

The Trustees (who are also directors of Genetic Alliance UK Ltd for the purposes 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 16 August 2022 and signed on the Board's behalf by:



**Elizabeth Porterfield**

**Chair**

Board of Trustees

# INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF GENETIC ALLIANCE UK

## Opinion

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2022 set out on pages 42 to 59 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 2022, 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 38 the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements

that are free from material misstatement, whether due to fraud or error.

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

## **Auditor’s responsibilities for the audit of the financial statements**

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

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

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

We gained an understanding of the legal and regulatory framework applicable to the company and the industry in which it operates and considered the risk of acts by the charity that were contrary to applicable laws and regulations, including fraud. We designed audit procedures to respond to the risk, recognising that the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting

from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

We focussed on laws and regulations which could give rise to a material misstatement in the financial statements, including, but not limited to, the Companies Act 2006.

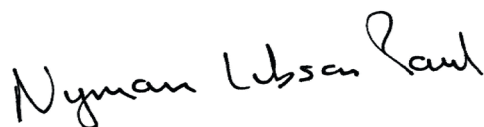
Our tests included agreeing the financial statement disclosures to underlying supporting documentation and enquiries with management. There are inherent limitations in the audit procedures described above and, the further removed non-compliance with laws and regulations is from the events and transactions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

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

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

## Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



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

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

Date: 16 August 2022

# ACCOUNTS

## GENETIC ALLIANCE UK LTD

### STATEMENT OF FINANCIAL ACTIVITIES (INCLUDING INCOME AND EXPENDITURE ACCOUNT)

YEAR ENDED 31 MARCH 2022

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2022 £	Total Funds 2021 £
<b>Income from:</b>					
Donations and legacies	2	383,619	273,835	657,454	933,883
Charitable activities	3	56,114	-	56,114	5,557
<b>Total income</b>		<b>439,733</b>	<b>273,835</b>	<b>713,568</b>	<b>939,440</b>
<b>Expenditure on:</b>					
Raising funds	4	95,416	-	95,416	105,444
Charitable activities	5	368,960	298,048	667,008	703,463
<b>Total expenditure</b>		<b>464,376</b>	<b>298,048</b>	<b>762,424</b>	<b>808,907</b>
<b>Net income/(expenditure)</b>	<b>8</b>	<b>(24,643)</b>	<b>(24,213)</b>	<b>(48,856)</b>	<b>130,533</b>
<b>Transfers between funds</b>	<b>19</b>	<b>(1,430)</b>	<b>1,430</b>	<b>-</b>	<b>-</b>
<b>Net movement in funds</b>		<b>(26,073)</b>	<b>(22,783)</b>	<b>(48,856)</b>	<b>130,533</b>
<b>Total funds at start of year</b>	<b>19</b>	<b>160,730</b>	<b>39,134</b>	<b>199,864</b>	<b>69,331</b>
<b>Total funds at end of year</b>	<b>19</b>	<b>134,657</b>	<b>16,351</b>	<b>151,008</b>	<b>199,864</b>

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 45 to 59 form part of these financial statements  
See note 11 for fund-accounting comparative figures

# GENETIC ALLIANCE UK LTD

## BALANCE SHEET

AS AT 31 MARCH 2022

Company number: 05772999

	Note	2022 £	2021 £
<b>Fixed assets</b>			
Tangible assets	12	992	-
		<u>992</u>	<u>-</u>
<b>Current assets</b>			
Debtors	13	66,149	126,373
Cash at bank and in hand		199,282	239,896
		<u>265,431</u>	<u>366,269</u>
<b>Liabilities</b>			
Creditors : amounts falling due within one year	14	(115,415)	(166,405)
		<u>150,016</u>	<u>199,864</u>
<b>Net current assets</b>			
		<u>150,016</u>	<u>199,864</u>
<b>Total assets less current liabilities</b>			
		<u>151,008</u>	<u>199,864</u>
<b>Net assets</b>			
		<u><u>151,008</u></u>	<u><u>199,864</u></u>
<b>FUNDS</b>			
<b>Unrestricted funds</b>			
General funds	20	55,109	62,409
Designated funds	20	79,548	98,321
<b>Restricted funds</b>			
	20	16,351	39,134
		<u>151,008</u>	<u>199,864</u>

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

These financial statements were approved by the Trustees on 16 August 2022 and are signed on their behalf by:



Liz Porterfield  
Chair of Trustees

**The notes on pages 45 to 59 form part of these financial statements**

**GENETIC ALLIANCE UK LTD**  
**CASH FLOW STATEMENT**  
**YEAR ENDED 31 MARCH 2022**

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	<b>Note</b>	<b>2022</b> <b>£</b>	<b>2021</b> <b>£</b>
<b>Net cash inflow from operating activities</b>	<b>16</b>	<b>(39,336)</b>	<b>127,841</b>
<b>Non-operational cash flows:</b>			
<b>Investing activities</b>			
Payments for tangible fixed assets		(1,278)	-
		<u>(1,278)</u>	<u>-</u>
<b>Net cash inflow/(outflow) for the year</b>	<b>17</b>	<u><u>(40,614)</u></u>	<u><u>127,841</u></u>

**Cashflow Restrictions**

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

**The notes on pages 45 to 59 form part of these financial statements**

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# GENETIC ALLIANCE UK LTD

## NOTES TO THE FINANCIAL STATEMENTS

### YEAR ENDED 31 MARCH 2022

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#### 1 Accounting policies

##### Accounting convention

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

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

##### Going concern

The charity faced additional challenges in the year as the economy began to recover from the economic and other consequences of the Covid-19 pandemic, with less government support, and fundraising in particular was impacted. These circumstances resulted in reduced revenue and an unrestricted fund deficit for the year of c £24k compared to a surplus for the previous year of £116k. Unrestricted free reserves (general and designated funds) stand at approximately £135k as at 31 March 2022 and these reserves continue to provide a buffer for the charity.

The Trustees have now reviewed the current circumstances of the Charity and updated budgets, forecasts and projections for the next 12 months have been prepared. Prudent assumptions with regard to income indicate that the Charity will break even for the year ending 31 March 2023 and indications to date are that the fundraising targets included within the budget will be met with the accounts to date showing in excess of 50% of those targets already met 4 months into the 2022/23 year. On the basis of these results and the reserves in hand, adequate liquid resources will continue to be available to fund the activities of the charity for the foreseeable future.

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

##### Income

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

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

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

Membership income is accounted for as receivable.

Investment income is included on a receivable basis.

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

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**1 Accounting policies (*continued*)**

**Expenditure**

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

**Raising funds**

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

**Charitable Activities**

Grants awarded are allocated to charitable activities.

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

**Governance costs**

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

**Allocation and apportionment costs**

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

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

**Pension costs and other post-retirement benefits**

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

**Fixed assets**

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

Depreciation is charged on assets at the following rates:

Office equipment - 3 years straight line

**Debtors**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

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**1 Accounting policies (*continued*)**

**Cash**

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

**Creditors**

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

**Fund accounting**

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

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

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

Further explanation of the nature and purpose of each fund is included in note 19 to the financial statements.

**2 Income from donations and legacies**

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

**GENETIC ALLIANCE UK LTD**  
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**2 Income from donations and legacies (*continued*)**

**Prior year**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2021 £</b>
Donations from supporters	397,745	185,235	582,980
Wellcome Trust	50,590	-	50,590
University College London	-	44,841	44,841
The Corra Foundation	-	36,805	36,805
National Lottery funding	-	25,907	25,907
City Bridge Trust	-	25,700	25,700
Edward Gostling	4,994	-	4,994
<i>Grants from Government</i>			
National Lottery funding	-	20,026	20,026
Scottish Government	-	9,821	9,821
Covid Job Retention Scheme fund	67,202	-	67,202
Other grants received	1,000	-	1,000
<i>Donations through fundraising:</i>			
Community fundraising	7,552	-	7,552
Online donations	55,327	1,138	56,465
	<u>584,410</u>	<u>349,473</u>	<u>933,883</u>

**3 Income from: Charitable activities**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2022 £</b>
Consultancy work	56,114	-	56,114
	<u>56,114</u>	<u>-</u>	<u>56,114</u>

**Prior year**

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2021 £</b>
Consultancy work	5,557	-	5,557
	<u>5,557</u>	<u>-</u>	<u>5,557</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

**4 Expenditure on: Raising funds**

	<b>Total Funds 2022 £</b>	<b>Total Funds 2021 £</b>
Staff costs, including consultancy work	87,483	62,938
Fees	1,438	2,990
Other direct costs	-	44
Support costs (Note 6)	6,495	39,472
	<u>95,416</u>	<u>105,444</u>

**5 Expenditure on Charitable activities**

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

**Prior year**

	<b>Direct Costs £</b>	<b>Support Costs (Note 6) £</b>	<b>Total Funds 2021 £</b>
Membership and Engagement	110,002	114,597	224,599
Policy work	122,778	194,119	316,897
Research	71,233	90,734	161,967
	<u>304,013</u>	<u>399,450</u>	<u>703,463</u>

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

£244,779 of the above support costs in notes 4 and 5 and £229,278 of direct costs relate to unrestricted funds spent during the prior year. £194,143 of support costs and £140,707 of direct costs relates to restricted funds spent during the prior year.

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

Support costs are allocated between raising funds and charitable activities on the basis of usage.

Support costs, included in notes 4 & 5, are as follows:

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

**Prior year**

	<b>Raising Funds</b>	<b>Charitable Activities</b>	<b>Total 2021</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Staff costs	32,455	271,435	303,890
Communications	1,637	13,691	15,328
Office and admin costs	5,380	44,999	50,379
Travel	-	231	231
Finance costs	-	889	889
Professional fees	-	58,005	58,005
Governance costs (Note 7)	-	10,200	10,200
	<u>39,472</u>	<u>399,450</u>	<u>438,922</u>

**7 Governance costs**

	<b>Total Funds 2022</b>	<b>Total Funds 2021</b>
	<b>£</b>	<b>£</b>
Auditor's fees - for audit services	8,100	7,200
Accounts review	3,000	3,000
	<u>11,100</u>	<u>10,200</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

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**8 Net income/(expenditure) for the year**

This is stated after charging:

	<b>2022</b>	2021
	£	£
Auditor's remuneration - for audit services	8,100	7,200
Trustees' travel expenses (2 trustees)	884	-
	<u>8,984</u>	<u>-</u>

No Trustee received any remuneration during the year.

**9 Staff costs and numbers**

The aggregate payroll costs were:

	<b>2022</b>	2021
	£	£
Wages & salaries	446,757	483,459
Social security costs	41,839	47,496
Pension contributions	25,283	33,650
Redundancy costs	8,338	33,901
	<u>522,217</u>	<u>598,506</u>

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

	<b>2022</b>	2021
Between £60,001 and £70,000	1	-
Between £70,001 and £80,000	<u>-</u>	<u>1</u>

The average weekly number of employees during the year was 17 (2021: 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 £181,356 (2021: £234,821).

**10 Taxation**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

**11 Statement of Financial Activities comparative figures**

<b>For the year ended 31 March 2021</b>	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2021 £</b>
<b>Income from:</b>			
Donations and legacies	584,410	349,473	933,883
Charitable activities	5,557	-	5,557
<b>Total income</b>	<u>589,967</u>	<u>349,473</u>	<u>939,440</u>
<b>Expenditure on:</b>			
Raising funds	105,444	-	105,444
Charitable activities	368,613	334,850	703,463
<b>Total expenditure</b>	<u>474,057</u>	<u>334,850</u>	<u>808,907</u>
<b>Net income/(expenditure)</b>	115,910	14,623	130,533
<b>Transfers between funds</b>	42	(42)	-
<b>Net movement in funds</b>	115,952	14,581	130,533
<b>Total funds at start of year</b>	44,778	24,553	69,331
<b>Total funds at end of year</b>	<u>160,730</u>	<u>39,134</u>	<u>199,864</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

**12 Tangible fixed assets**

	<b>Office equipment £</b>	<b>Total £</b>
<b>Cost or valuation</b>		
At 1 April 2021	-	-
Additions	1,278	1,278
At 31 March 2022	<u>1,278</u>	<u>1,278</u>
<b>Depreciation</b>		
At 1 April 2021	-	-
Charge for the year	286	286
At 31 March 2022	<u>286</u>	<u>286</u>
<b>Net book value</b>		
At 31 March 2022	<u>992</u>	<u>992</u>
At 31 March 2021	<u>-</u>	<u>-</u>

**13 Debtors**

	<b>2022 £</b>	<b>2021 £</b>
<b>Due in less than one year:</b>		
Trade debtors	47,136	125,729
Prepayments and accrued income	17,813	-
Other debtors	1,200	644
	<u>66,149</u>	<u>126,373</u>

**14 Creditors: amounts falling due within one year**

	<b>2022 £</b>	<b>2021 £</b>
Trade creditors	6,165	7,551
Social security and other taxes	20,617	11,248
Other creditors	4,320	3,446
Accruals and deferred income	84,313	144,160
	<u>115,415</u>	<u>166,405</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

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**15 Operating lease commitments**

At 31 March 2022, the charity had future minimum lease payments under non-cancellable operating leases as follows:

	Equipment	
	2022	2021
	£	£
Expiry Date:		
Not later than one year:	-	5,171
	<u>-</u>	<u>5,171</u>

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

	2022	2021
	£	£
Statement of Financial Activities: Net movement in funds	(48,856)	130,533
Depreciation	286	-
(Decrease)/increase in creditors: current liabilities	(50,990)	(23,174)
Decrease / (increase) in debtors	60,224	20,482
<b>Net cash inflow/(outflow) from operating activities</b>	<u><u>(39,336)</u></u>	<u><u>127,841</u></u>

**17 Analysis of changes in cash during the year**

	2022	2021	Change
	£	£	£
Cash at bank and in hand	<u>199,282</u>	<u>239,896</u>	<u>(40,614)</u>
	2021	2020	Change
	£	£	£
Cash at bank and in hand	<u>239,896</u>	<u>112,055</u>	<u>127,841</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

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**18 Analysis of changes in net debt**

	<b>1 April 2021 £</b>	<b>Cashflow Movements £</b>	<b>31 March 2022 £</b>
Cash at bank and in hand	239,896	(40,614)	199,282
	<u>239,896</u>	<u>(40,614)</u>	<u>199,282</u>
Prior year	<b>1 April 2020 £</b>	<b>Cashflow Movements £</b>	<b>31 March 2021 £</b>
Cash at bank and in hand	112,055	127,841	239,896
	<u>112,055</u>	<u>127,841</u>	<u>239,896</u>

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

**19 Movement in Funds**

For the year ended 31 March 2022

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

**Fund descriptions**

**Restricted funds**

**Scotland Boost** - funds received for the dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions.

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

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
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**19 Movement in funds (*continued*)**

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

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

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

**Building Rare Resilience** - This was the second instalment of restricted funding from the National Lottery Covid-19 emergency fund for the Building Rare Resilience project.

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

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

**Rare Resources** - funds are restricted to the development and dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions.

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

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

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

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

**Rare Disease Day** - funds received to help with the costs of putting on our annual Rare Disease Day.

**Genomic Data** - funds were received to complete work to understand the attitudes of people living with genetic, rare and undiagnosed conditions and storage of their data.

**Covid-19** - funds received to help with the challenges associated with Covid-19.

**Designated funds**

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

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

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
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**19 Movement in funds (continued)**

For the year ended 31 March 2021

	At 1 April 2020 £	Income £	Expenditure £	Transfers £	At 31 March 2021 £
<b>Restricted funds</b>					
Rare Disease Day 2018	28	-	(28)	-	-
Scotland Boost	-	9,821	(8,512)	-	1,309
Action for Access	13,047	10,000	(4,646)	-	18,401
Concord	1,061	44,841	(45,902)	-	-
RD PSPs	6,881	-	(1,439)	-	5,442
SWAN UK: Dads' Summit	-	6,364	(6,364)	-	-
SWAN UK Wales	-	25,907	(15,979)	-	9,928
Genomic Data	42	-	-	(42)	-
Building Rare Resilience	-	20,026	(20,026)	-	-
Talking about Gene Therapy	3,494	10,000	(9,440)	-	4,054
Patient survey	-	38,600	(38,600)	-	-
Rare Resources	-	2,846	(2,846)	-	-
Covid-19	-	158,505	(158,505)	-	-
Rare Disease Day	-	22,563	(22,563)	-	-
	<u>24,553</u>	<u>349,473</u>	<u>(334,850)</u>	<u>(42)</u>	<u>39,134</u>
<b>Unrestricted funds</b>					
General funds	44,778	182,069	(162,607)	(1,831)	62,409
<b>Designated funds</b>					
Rare Disease Day	-	60,000	(25,133)	-	34,867
Rare Disease UK General Donations	-	290,748	(227,294)	-	63,454
SWAN UK: General Donations	-	57,150	(59,023)	1,873	-
	<u>44,778</u>	<u>589,967</u>	<u>(474,057)</u>	<u>42</u>	<u>160,730</u>
<b>Total funds</b>	<u>69,331</u>	<u>939,440</u>	<u>(808,907)</u>	<u>-</u>	<u>199,864</u>

**20 Analysis of net assets between funds**

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

**GENETIC ALLIANCE UK LTD**  
**NOTES TO THE FINANCIAL STATEMENTS**  
**YEAR ENDED 31 MARCH 2022**

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**20 Analysis of net assets between funds (continued)**

<b>As at 31 March 2021</b>	<b>Restricted Funds £</b>	<b>Unrestricted Designated Funds £</b>	<b>Unrestricted General Funds £</b>	<b>Total £</b>
Bank and cash	39,134	98,321	102,441	239,896
Other net assets	-	-	(40,032)	(40,032)
	<u>39,134</u>	<u>98,321</u>	<u>62,409</u>	<u>199,864</u>

**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.

# ACKNOWLEDGEMENTS

Thank you to all 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 our funders who have given grants, sponsorship or donations to support our work this year. These organisations are listed here.

Thank you to the SWAN UK families who have given us permission to use photographs of their beautiful children in this report.

Albireo Pharma  
Alexion Pharma  
Amicus Therapeutics  
Barratt Charity Foundation  
BioCryst UK Limited  
Biogen Idec Limited  
Catherine Cookson Charitable Trust  
Chiesi Ltd  
CRD Consulting  
Edward Gostling Foundation  
Gilead Sciences Ltd  
HFEA  
HRA Pharma Rare Diseases  
Hugh Fraser Foundation  
Incyte Biosciences UK Ltd  
Intent Health  
Ionis Pharmaceuticals  
Joicey Trust  
Sir Jules Thorn Charitable Trust  
Kyowa Kirin Ltd  
Marjory Boddy Charitable Trust  
Medpace UK Ltd  
Melton Mowbray Foundation  
National Lottery Trust  
Novartis Gene Therapies  
Novartis Pharmaceuticals UK Ltd  
Oakdale Trust  
Orchard Therapeutics  
Persimmon Charitable Foundation  
PF Charitable Trust  
Pfizer Limited  
PTC Therapeutics  
Great Ormond Street  
Rhythm Pharmaceuticals  
Robert Luff Trust  
Roche Products Limited  
Russell Trust  
Sanofi Genzyme  
Scottish Government  
SOBI UK Ltd  
Takeda UK Limited  
Triducive Partners Ltd  
UCB Pharma Limited  
UCL Research  
Vertex Pharmaceuticals  
Wellcome Trust

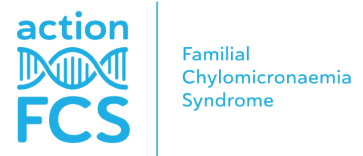
# OUR MEMBERS



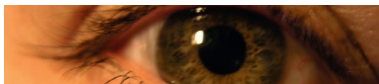
The Aarskog Foundation



Action Duchenne



Action FCS



Action on Gilbert's Syndrome



Addison's Disease Self-Help Group



Adrenal Hyperplasia Network



Advocacy for Neuroacanthocytosis Patients



Albinism Fellowship UK Ireland



Alex, The Leukodystrophy Charity



ALK Positive Lung Cancer (UK)



Alkaptonuria Society



Alpha-1 Awareness UK



Alpha-1 UK Support Group



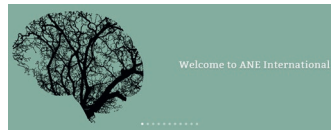
Alport UK



Alström Syndrome UK



Amy and Friends



ANE International



Angelman UK



Aniridia Network



Annabelle's Challenge



Anorchidism Support Group



Antenatal Results and Choices



Archangel Mld Trust



Association For Glycogen Storage Diseases UK



Ataxia UK



Ataxia-Telangiectasia Society



Bardet-Biedl Syndrome UK



Barth Syndrome UK



Batten Disease Family Association



Beat SCAD



Beckwith Wiedemann Support Group

Beckwith-Wiedemann Support Group UK



Behçet's UK



BRCA Umbrella



British Heart Foundation



Cadasil Support UK



Cambridge Rare Disease Network



Cardiomyopathy UK



Cavernoma Alliance UK



CdLS Foundation UK and Ireland



CGD Society



CHAMP1 Patient Support Group



Charcot-Marie-Tooth UK



Childhood Tumour Trust



Children's Liver Disease Foundation



Children's Mitochondrial Disease Network



Children's Health Scotland



CML Support Group



Congenital Adrenal Hyperplasia Support Group



Costello Support Group International



Cri Du Chat Syndrome Support Group



Cure and Action for Tay-Sachs Foundation



Cure Myotonic Dystrophy UK Charity



Cystic Fibrosis Trust



Cystinosis Foundation UK



DC Action



DDDC3G Renal Support Group UK



Dercums Disease and Rare Disease Foundation UK



Diamond Blackfan Anaemia Support Group UK



Dravet Syndrome UK



Duchenne Family Support Group



East Lancashire Community Genetics Service



East London Branch Sickle Cell Society



Ehlers-Danlos Society



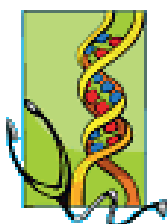
EHLERS-DANLOS SUPPORT UK



ELIJAH'S HOPE



FANCONI HOPE CHARITABLE TRUST



Fap Gene Support Group



Fibromuscular Dysplasia Society



Fibrous Dysplasia Support Society UK



Fight for Sight



Findacure



FND Hope UK



FSH Muscular Dystrophy Support Group



Fuchsfriends UK



Funny Lumps



GATA2 Deficiency Support Group



GENE People UK



George Pantziarka TP53 Trust



GIST Support UK



Gorlin Syndrome Group



Hadiza Foundation



HAE UK



Haemochromatosis UK



Haemophilia Society



Headlines Craniofacial Support



Hereditary Spastic Paraplegia Group



Hope for Hasti



HPS Network UK



Huntington's Disease Association UK



Hypermobility Syndromes Association



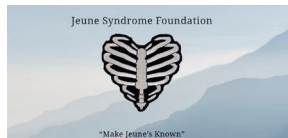
Ichthyosis Support Group



IiH UK



Inherited Prion Disease Support Group



Jeune Syndrome Foundation



Jnetics



KIF1A.ORG



Kleefstra Syndrome



Krabbe UK



Leber's Hereditary Optic Neuropathy Society



Lipodystrophy UK



Local Families With Bleeding Disorders



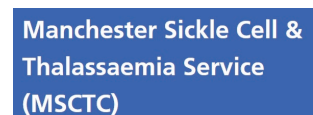
Lynch Syndrome UK



Macular Society



Making It Better - The Daniel Courtney Trust



Manchester Sickle Cell and Thalassaemia Centre



Marfan Trust



Mast Cell Action



Max Appeal



MEBO Research



Medics 4 Rare Diseases



Metabolic Support UK



Moebius Research Trust



Motor Neurone Disease Association



Mowat-Wilson Syndrome Support Group



MPGN/DDD Support Group



Muscle Help Foundation



Muscular Dystrophy UK



Myotubular Trust



Naitbabies



Narcolepsy UK



National Deaf Children's Society



NCBRS Worldwide Foundation



Nemaline Myopathy Support Group



Nerve Tumours UK



Neuroendocrine Cancer UK



NF2 BioSolutions



Niemann-Pick UK



NLRP12.COM



Noonan Syndrome Association



Northern Ireland Rare Disease Partnership



Ocumel UK



Osteopetrosis Support Trust



Pans Pandas UK



Parathyroid UK



Pemphigus Vulgaris Network



Pitt Hopkins UK



PNH Support Group



Poland Syndrome Support & Network



Prader-Willi Syndrome Association UK



Primary Ciliary Dyskinesia Family Support Group



Supporting families affected by primary and secondary immunodeficiency

Primary Immunodeficiency UK



PSC Support Group



Pseudoxanthoma Elasticum Support Group



PTEN UK and Ireland Patient Group



Rare Autoinflammatory Conditions Community - UK



Rare Dementia Support



RETT UK



Reverse RETT



RING20 Research and Support UK



SADS UK



Salivary Gland Cancer UK



Sarcoidosis UK



Schinzel-Giedion Syndrome Foundation



Scleroderma And Raynaud's UK



Sense Usher Service



Shwachman-Diamond Support UK



SOFT UK



Special Needs Jungle



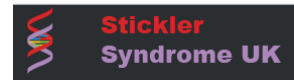
Spinal Muscular Atrophy UK



Spotlight YOPD



Stargardt's Connected



Stickler Syndrome UK



Stiff Person Syndrome



Syngap Research Fund



Thalidomide Society



The Aortic Dissection Charitable Trust



The Aplastic Anaemia Trust



The British Porphyria Association



The Children's Hyperinsulinism Charity



The Fragile X Society



The Gauchers Association



The Lily Foundation



The Maddi Foundation



The MPS Society



The Smith-Magenis Syndrome Foundation UK



The UK Mastocytosis Support Group



Thyroid UK



Timothy Syndrome Alliance



TreatSMA



TRPS Support Group UK



Tuberous Sclerosis Association



Turner Syndrome Support Society UK



UK LGLL



UK Thalassaemia Society



UKPIPS



Unique – Understanding Chromosome Disorders



Urddad Foundation



Vasculitis UK



VHL UK/Ireland



Williams Syndrome Foundation Limited



Wilson's Disease Support Group UK



Wolfram Syndrome UK



Womb Cancer Support UK



Worster-Drought Syndrome Support Group



XLP Research Trust



**XP Support Group**



**Yellow Brick Road  
Project Inc**



Registered company number: 05772999  
Registered charity numbers: 1114195 and SC039299  
Registered office: Creative Works, 7 Blackhorse Lane, London, E17 6DS

**GENETIC ALLIANCE UK LTD**

England & Wales - Charity number 1114195

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# Accounts

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# GENETIC ALLIANCE UK

Report of the Board of Trustees and Accounts  
2020-2021



**GENETIC  
ALLIANCE** UK

# REPORT OF THE BOARD OF TRUSTEES

For the year ended 31 March 2021

**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 2021. The trustees have adopted the provisions of the 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 2015) and the Companies Act 2016.**

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### Genetic Alliance UK

[contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

[geneticalliance.org.uk](http://geneticalliance.org.uk)

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

# WELCOME FROM THE CHAIR



If I may, I will begin by thanking everyone for their hard work in what has been a tumultuous year for everyone — in our case, for our members, our communities, our team and the Board of Genetic Alliance UK. Tumultuous yes, but also

enlightening and, I'm particularly glad to say, successful. Covid-19 has undoubtedly severely impacted on all of us in one or more ways. At the same time, it has led us to look at new ways of working, both within the organisation and with our members and their families throughout the land. Our weekly Community check-ins have proven to be valuable to many in our community and such has been the success of their collaborative approach that we will continue with them, working with, and keeping in touch, with what matters to you – our families and carers.

It is unfortunate that some of our public affairs activities were necessarily truncated this year, largely due to most of our team being on furlough for several months. For those team members who remained, the road has been long and hard. That we have succeeded in so many areas is due to their unstinting efforts, for which I and the rest of the Board are enormously grateful.

There have also been challenges with fundraising and with the departure of our Chief Executive, Jayne Spink, at the end of March. To allow time for consolidation and stability in what was already a turbulent time, the board decided to appoint two joint interim chief executives, Nick Meade, Director of Policy and Lauren Roberts, Director of Engagement and Support, rather than proceed immediately to appoint a new CEO. This arrangement is ongoing and the Board will consider when and how best to fulfil the CEO role in the light of experience.

As far as fundraising is concerned, this continues to be a challenging area. Having succeeded in appointing a Director of Fundraising toward the end of the year, unfortunately personal circumstances meant that the postholder had to resign within a short time. It is to her credit

however that in the few months she was with us, she undertook a robust review of fundraising and generated a new strategy which is now being pursued.

The Genetic Alliance UK Board has also taken the opportunity to look at how we work together and consider our governance responsibilities and arrangements to ensure we keep pace with, and meet, the expectations of the Charities Commissions in England and Wales and Scotland. This work is ongoing but has led to what we hope will be improved information and support for Trustees in the future. There is no doubt that remote working has brought with it some challenges and we are all looking forward to a time, hopefully soon, when we might be able to meet again in person.

It also gives me great pleasure to look forward to working with the four administrations across the UK as they work towards implementation of the new Rare Disease Strategy launched in February. This, and the launch of Genome UK, are particular highlights in what we hope will be new and exciting opportunities for everyone affected by rare, genetic and/or undiagnosed conditions to seek and see ongoing improvements in diagnosis, treatment and care.

As we look over the year it is with hopes of continued success in meeting the challenges faced not only by us, but most charities, as we all look to the future in a new light, living with and, hopefully, post Covid-19.

I commend this annual report to you, which is possible only through the work of the Genetic Alliance UK team and built on the experiences and hopes of families and carers throughout the UK.

A handwritten signature in black ink, appearing to read 'Elizabeth Porterfield'.

**Elizabeth Porterfield**  
Chair, Board of Trustees  
Genetic Alliance UK

# OBJECTIVES AND AIMS

**Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by genetic, rare and undiagnosed conditions. We are an alliance of over 200 patient organisations.**

**The objectives of the charity are to:**

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

We advocate for fast and accurate diagnosis, good quality care and access to the best treatments. We actively support progress in research and engage with decision makers and the public about the challenges faced by our community.

## **Public benefit**

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit and have complied with their duty under section 4 of the Charities Act 2011 when reviewing the charity's aims and objectives; and in implementing current and planning future activities.

# TERMINOLOGY WE USE

A word about our terminology:

## **Genetic, rare and undiagnosed**

We support people with genetic, rare and undiagnosed conditions. Sometimes our work might focus particularly on a subset of these groups, such as with our SWAN UK (syndromes without a name) support network for families with children with undiagnosed conditions.

**A genetic condition** is one that is caused by a change in an individual's genome. (A genome is your complete set of genetic instructions. Each genome contains all of the information needed to build you and allow you to grow and develop.) The change might be a single letter of the DNA code added, deleted or rearranged, or a much bigger change with more of the genome added, deleted or rearranged.

**A rare condition** is one that affects fewer than 1 in 2,000 people in the UK. Almost all genetic conditions are rare. There are a handful of genetic conditions that are not rare, we support people with these conditions too. About 72% of rare conditions are genetic. We expect this proportion to grow with progress in genomic research. We support everyone living with a rare condition.

**A syndrome without a name** or undiagnosed genetic condition is a genetic condition that has not been diagnosed yet. This might be because the right test has not been carried out to make the diagnosis yet, or because the particular genetic cause of the condition has not been discovered yet. We support all families with children with undiagnosed genetic conditions.

## **Condition and disease**

We prefer to use the term 'condition' as much as possible. This is because our members and the people they support prefer it. 'Disease' and 'condition' are technically interchangeable terms, but 'disease' has more negative connotations and for some implies that the condition might be contagious. We do have to use the term 'disease' sometimes, this is because the term 'rare disease' has a lot of traction at policy level. We named our campaign Rare Disease UK accordingly, and key UK policies such as the outgoing UK Strategy for Rare Diseases and the UK Rare Diseases Framework also use the term.

# IMPACT OF COVID-19

## COMMUNITY SUPPORT PROGRAMME

In response to the pandemic we quickly initiated new activities to support the whole genetic, rare and undiagnosed community. This included developing a **new information hub** that was updated regularly and signposted to condition specific information, and holding a weekly virtual Community check-in for organisations to work together to share information and ideas. As a result of these sessions we were able to quickly identify and proactively respond to a number of issues facing our community.

These included **alerting NICE to problems with the use of the clinical frailty score** for people with rare conditions, working with WellChild to resolve issues around getting children with rare conditions back to school due to the aerosol generating procedures guidance, and **successfully campaigning for people affected by rare conditions to be on the priority list for Covid-19 vaccinations**.

- **45 virtual community check-ins hosted**
- **Attended by 325 individuals**
- **150 organisations represented**
- **16K users visited our Covid-19 information hub**
- **Information hub pages viewed over 38K times**

## THE RARE REALITY OF COVID-19

The pandemic caused sudden and, for many in our community, devastating changes to their lives.

Using UK specific data from the EURORDIS Rare Barometer Covid-19 Experience Survey, and findings from our weekly community check-ins during the months of April, May and June 2020, we produced a report, '**The Rare Reality of Covid-19**'. This highlighted how people living with rare conditions had been placed under immense

### Key findings from the Rare Reality of Covid-19 report:

- **66% felt their healthcare disruptions were detrimental to their wellbeing**
- **40% reported closure of their hospital units**
- **20% of people had access to their medication disrupted**
- **40% feared Covid-19 posed a high threat to their health**

pressure by the pandemic. Access to appropriate support, information, care and treatments had become more difficult and levels of social isolation had increased.

The report was shared with parliamentarians from the All Party Parliamentary Group (APPG) and Cross Party Groups (CPGs) on Rare, Genetic and Undiagnosed Conditions in Westminster, Wales and Scotland. On the same day, the report was attached to a letter to the Secretary of State for Health and Social Care and the minister responsible for rare diseases in England with two clear immediate asks: a risk assessment tool for Covid-19 and people with rare conditions to assist future shielding messaging; and an examination of telemedicine during the crisis period, to ensure best practice is maintained while services are restored.

The report was also promoted at the CPGs in Scotland and Wales and in the November **2020: APPG meeting on Covid-19** that focussed on the impact of Covid-19 on the rare, genetic and undiagnosed community. Over 80 people attended the meeting.

## BUILDING RARE RESILIENCE

Identifying high levels of stress and signs of burn out in our community, we partnered with Rare Minds to offer group counselling to organisation leaders and SWAN UK parents. Over 50 people benefited from this pilot, and participants from Genetic Alliance UK organisations continue to meet.

# DRIVING PROGRESS

## POLICY AND PUBLIC AFFAIRS

Despite Covid-19, this has been a year of ongoing progress in key areas of work for Genetic Alliance UK and our members.

### Genomics

In genomics, the NHS Genomic Medicine Service continued to build towards the roll out of the full service, and we were able to contribute through our connection to the UK National Genomics Board and NHS England's Genomics Board. We also welcomed the publication of the [UK's new genomic strategy, Genome UK](#).

### NICE methods and process review

The NICE methods and process review presents an opportunity to improve access to medicines for rare conditions. Our team had a position on the working group throughout the year, and we contributed to the methods review consultation and the consultation on topic selection.

### UK Rare Diseases Framework

Most importantly the [UK Rare Diseases Framework](#) was published in January 2021, just in time to take over from the UK Strategy for Rare Diseases which ended in 2020. Members of our Rare Disease UK Patient Empowerment Group from across the UK played a key role in advising on the development of the Framework, and since publication we have switched our attention to supporting the development of action plans in the four nations. We were delighted when the chair of the All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed conditions secured a Westminster Hall debate on rare diseases.

In 2019, Genetic Alliance UK published two important reports, our [Patient Charter on newborn screening](#), and our [Action for Access](#) report on access to medicines for rare conditions. Our original plan for 2020 was to promote the messages in these reports, and take forward these issues for our community. We had to shelve these plans, and intend to review these issues at the beginning of the next year to reframe them in the context of Covid-19, and take them forward in collaboration with our members.

### Patient voice in policy development

We provided input to an Medicines and Healthcare products Regulatory Agency Patient Group Consultation Event on Regulatory Flexibilities during Covid-19 and a consultation event held by the Department of Health and Social Care (DHSC) regarding feedback on the initial draft of the new UK Framework for Rare Diseases.

We continue to input as a patient representative member to the Rare Disease Implementation Group (RDIG) which has oversight for the Welsh Action Plan and Genomics Partnership Wales Sounding Board. Throughout the last year, we fed in the experience of people living with rare conditions during the pandemic via the Rare Disease Implementation Group lead and lead commissioner for the Welsh Health Specialised Services Committee (WHSSC). We also fed in issues affecting the rare disease community via the Welsh Government Third Sector Stakeholder Forum.

### Cell and gene therapy engagement workshops

We received over 100 applications to take part in a series of three virtual workshops on cell and gene therapy that took place in November and December 2020. We selected a small cohort of 20 candidates to take part with the recordings of the workshops sent to the remaining applicants alongside a survey.

[‘I felt all areas were well covered and especially appreciate the fact that they were moderately geared to the understanding of those of us who had little prior knowledge. The extra reading resources and videos contributed to such a lovely comprehensive seminar.’](#)

The purpose of these workshops was to follow up on the previous work with Progress Educational Trust on Understanding Genome Editing with the aim of educating people with experience of living with a genetic or rare condition about cell and gene therapy. It was also to prepare a report which describes the priorities of our community in learning about cell and gene therapy.

The project is ongoing and will be completed in the autumn of 2021.

# WALES

## Genomics Partnership Wales Patient and Public Sounding Board consultations

We worked with Genomics Partnership Wales to recruit the second cohort of 11 new members to the Patient and Public Sounding Board which provides patient and public advice and input to the work of the Genomics of Precision Medicine Strategy and its programme of work.

We held three meetings of the Board in the reporting period for 2020 and two in the reporting period for 2021 (28 April 2020, 14 July 2020, 8 October 2020, 19 January 2021, 15 April 2021).

Topics included: input to the design and development of a new estates building bringing together genomic testing, clinical facilities and genomic research in Wales and feedback on patient and public involvement in other programmes including pathology, imaging and advanced therapies.

Coproduced with members, [an impact video](#) has been created to showcase the impact members have made through being involved with the Board.

### Cross Party Group meetings

The Welsh Cross Party Group (CPG) for Rare, Genetic and Undiagnosed Conditions held its inaugural meeting in the Senedd in September 2019. Since then, the group, chaired by Angela Burns MS and administered by Genetic Alliance UK, has heard a broad range of people's experiences. Over the last 12 months, meetings have moved to a virtual platform and we have been able to feed back experiences directly to Welsh Government through the third sector stakeholder forum.

September 2020: The first virtual meeting of the CPG since the start of the pandemic focused on the immense pressure Covid-19 was putting on people living with rare conditions. Reports highlighted difficulties gaining access to appropriate support, information, care and treatment and an increased level of social isolation had a detrimental impact on mental health.



Genetic Alliance UK @GeneticAll\_UK · Sep 21, 2020

Thank you to everyone who attended and to @AngelaJBurns for chairing the Welsh Cross Party Group meeting today on the impact COVID-19 has had on the rare, genetic and undiagnosed community. #RareDisease Read the full report here [covid-19.geneticalliance.org.uk/wp-content/upl...](https://covid-19.geneticalliance.org.uk/wp-content/upl...)



January 2021: The final meeting of the CPG ahead of the Senedd elections in 2021 examined the future for individuals and families affected by rare conditions in Wales. Key findings from Genetic Alliance UK's Rare Experience Report 2020 were presented and alignment to the priorities in the new UK Rare Diseases Framework were highlighted. Discussion focused on priorities for the implementation of a Welsh Action Plan.

February 2021: Angela Burns MS, Chair of the Welsh Cross Party Group **launched the final report** of the Cross Party Group for Rare, Genetic and Undiagnosed Conditions. Chair of the Rare Disease Implementation Group, Dr Graham Shortland spoke about Wales' plans for implementing the Framework and two guest speakers highlighted their experiences of life with Turner Syndrome.

Bringing together people affected by rare conditions, patient group representatives, health care professionals and researchers, the report identifies a series of recommendations which would improve the lives of people affected by rare conditions across four broad themes:

- The effect of rare conditions on mental health
- Access to orphan medicines
- The impact of Covid-19 on those affected by rare conditions
- A future Welsh Action Plan to implement the UK Rare Diseases Framework

# CROSS PARTY GROUP ON RARE, GENETIC & UNDIAGNOSED CONDITIONS

Final Report 2021



**GENETIC  
ALLIANCE** UK

# SCOTLAND

## Cross Party Group meetings

The Cross Party Group (CPG) on Rare, Genetic and Undiagnosed Conditions adopted virtual meeting practices from March 2020 and continued to provide a forum for people living with rare, genetic and undiagnosed conditions to come together to discuss and debate key issues. Since March 2020 the CPG has held five meetings.

May 2020: The first virtual meeting of the CPG was an opportunity to address the significant challenges affecting the community in the first months of the Covid-19 pandemic. Professor Jason Lietch, National Clinical Director for NHS Scotland, attended the meeting to provide an in depth question and answer session and to hear the experiences directly from group members.

October 2020: The impact of Covid-19 was addressed again with a presentation of Genetic Alliance UK's 'The Rare Reality of Covid-19 Report'.

January 2021: The CPG held a meeting focused on the vaccination programme.

November 2020: The CPG meeting was attended by the CoOrdinated Care Of Rare Diseases (CONCORD) study team who provided an overview of their findings on the principles of care coordination. This session informed the development of the CPG's report, 'Improving Care for Rare Conditions in Scotland', which was agreed at the final meeting of the CPG in March 2021.

June 2021: Due to the 2021 Scottish Parliament election, the current CPG ceased to exist on 26 March 2021. Following the election, work has been undertaken to re-establish the CPG, and a first meeting of the new CPG will be held in June 2021.

## Scotland policy – 'Improving Care for Rare Conditions in Scotland' report

On 23 March 2021, the Cross Party Group published the '[Improving Care for Rare Conditions in Scotland](#)' report.

The report provides a narrative of experiences raised with the Cross Party Group in the 2016-2021 parliamentary session and outlines what is needed to increase awareness of rare conditions among healthcare professionals and to improve coordinated care in Scotland.

'Improving Care for Rare Conditions in Scotland' calls for the development of a funded Rare Conditions Coordination Service for Scotland.

The report is intended to inform implementation of the UK Rare Diseases Framework and the development of the new Scottish Action Plan for Rare Diseases.

## Engagement networks

In Scotland, work is underway to formalise the way in which we engage and involve people in our work. Through the development of engagement and involvement networks, we will seek to build a strong multi-stakeholder community.

We have developed the [Scottish Virtual Involvement Panel](#) for people living with, or caring for someone living with, a rare, genetic or undiagnosed condition in Scotland. Our Virtual Involvement Panel will be at the heart of our work in Scotland and will provide our 'VIPs' (Virtual Involvement Panelists) an opportunity to contribute to our work and wider policy and service development decisions.

Virtual Involvement Panelists receive regular, information e-newsletters with news about developments in health and social care services. They will also be invited to attend a programme of digital events, contribute their experience for media work and be invited to take part in surveys and consultation events to shape policy and services in Scotland.

The Virtual Involvement Panel will play an important role in the development of the Scottish Rare Diseases Action Plan, as Genetic Alliance UK will be working closely with the Scottish Government to ensure people living with rare conditions are actively involved in the development and implementation of the plan.

Work is also underway to develop a Policy Involvement Network to bring together patient organisations in Scotland to have their say on genomic, rare disease and other relevant policy being developed by the Scottish Government and NHS Scotland. We are also growing our Professional Engagement Network, bringing together professionals working in health and social care in Scotland with an interest in rare, genetic and undiagnosed conditions to provide them with relevant information, training opportunities and the option to share their views on our policy work.

# IMPROVING CARE FOR RARE CONDITIONS IN SCOTLAND

A report by the Cross Party Group of Rare, Genetic and Undiagnosed Conditions



**GENETIC  
ALLIANCE** UK

# RESEARCH

We were fortunate that the impact of the Covid-19 pandemic on our two major research projects was minimal. Data collection for the CONCORD study on care coordination was largely complete before the first wave. We switched the face-to-face CONCORD workshops planned for summer 2020 to online events, which had the positive effect of allowing more geographically diverse groups to attend. The 2020 Rare Experience survey was always going to be an online activity, and again we were able to hold online workshops to test the findings in lieu of face-to-face meetings. The pressures facing our community meant that activities aimed at upskilling our members in research techniques were deprioritised but we hope to revitalise them in the forthcoming year.

The number of external researchers seeking our support for their studies increased as many Covid-19-specific projects were launched. We promoted good quality studies that were relevant to people with rare conditions to our networks, including bringing academic speakers into our community check-ins, and we have developed new ongoing relationships with researchers as a result. We also supported our member Ataxia UK to design their own survey and analyse the results, and co-presented findings at Ataxia UK events.

## Coordinated Care of Rare Diseases (CONCORD)

We have now finished the data collection and analysis for the CONCORD project which were presented at a [virtual meeting](#) attended by 170 people and [published on our website](#). The results were also presented as a poster at the European Conference on Rare Diseases (ECRD). See page 13).

Collaboration with external researchers has led to publication of the following peer-reviewed papers co-authored by members of our research team:

- **Simpson A**, Bloom L, Fulop NJ, Hudson E, Leeson-Beevers K, Morris S, Ramsay AIG, Sutcliffe AG, Walton H, **Hunter A**. How are patients with rare diseases and their carers in the UK impacted by the way care is coordinated? An exploratory qualitative interview study. Orphanet Journal of Rare Diseases 2021; 16: 76.

- Hammond J, Garner I, Hill M, Patch C, **Hunter A**, Searle B, Sanderson SC, Lewis. Animation or leaflet: Does it make a difference when educating young people about genome sequencing? Patient Education and Counseling, 2021. In press.

## Rare Experience 2020 report

Over 1,000 people responded to our five-yearly survey and 11 attended our follow up workshops. [The Rare Experience 2020 report](#) was launched in December 2020 with over 80 people in attendance.

This was the third comprehensive survey Genetic Alliance UK has undertaken to capture the experiences of people affected by rare conditions. It is seven years since the publication of the UK Strategy for Rare Diseases and a decade since we published the report of our first comprehensive survey - a decade in which we have seen significant progress in science, medicine and in terms of awareness of rare conditions.

Our 2020 survey provided a measure of the extent to which these advances have filtered through to impact on the lives of those affected by rare conditions, how their experiences have changed across the last decade, and a baseline against which we might judge future progress.

Whilst satisfaction remains high amongst those who have access to specialist care and treatment for their condition, we see few improvements for the majority of those who do not. The diagnostic odyssey remains a major challenge and new genomic services have yet to deliver on the promise of early and accurate diagnoses. The scale and frequency at which patients and families experience challenges relating to coordination of care seems to have been unaltered by the passage of time. Despite the commitments made in the UK Strategy, which came without specific financial resources dedicated to its implementation, there remains much to be delivered.

### Messages from the Rare Experience 2020 report included:

- [People with rare conditions are insufficiently served by the system](#)
- [Diagnosis is crucial](#)
- [Awareness of rare conditions among professionals is valuable and needs improving](#)
- [Professional care coordination is rare but necessary](#)
- [Pockets of excellence can demonstrate how the system can deliver](#)

# RARE EXPERIENCE 2020

The lived experiences of people affected by genetic, rare and undiagnosed conditions



**GENETIC  
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# HOW ARE PATIENTS WITH RARE DISEASES AND THEIR CARERS IMPACTED BY THE WAY THEIR CARE IS COORDINATED IN THE UK?

## An exploratory qualitative interview study

Amy Simpson<sup>\*1</sup>, Naomi Fulop<sup>2</sup>, Emma Hudson<sup>3</sup>, Stephen Morris<sup>3</sup>, Angus Ramsay<sup>2</sup>, Holly Walton<sup>2</sup> & Amy Hunter<sup>1</sup> (on behalf of the CONCORD study team)

<sup>1</sup>Genetic Alliance UK; <sup>2</sup>University College London; <sup>3</sup>University of Cambridge

Contact: amy.simpson@geneticalliance.org.uk / +44(0)20 7704 3141 / www.geneticalliance.org.uk

### Background

UK policy frameworks highlight the importance of care coordination for rare conditions. Yet, there is a lack of evidence exploring if and how patients and carers are impacted by the way in which their care is coordinated. We aimed to explore how care coordination (or lack of) impacts on patients and carers.

### Method

We conducted semi-structured interviews with 15 UK-based patients and carers/parents with lived experience of a range of rare and undiagnosed conditions. Transcript data were grouped into themes and sub-themes.

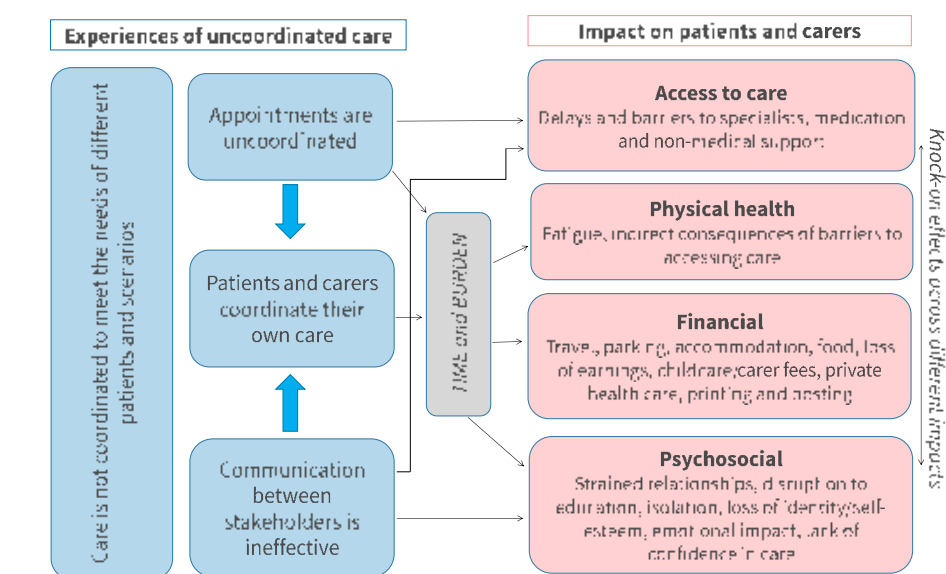
### Findings

- Participants reported that their care was uncoordinated in four key ways (see 'experiences of uncoordinated care' in figure 1)
- Patients and carers were negatively impacted in terms of their finances, psychosocial and physical wellbeing, and access to care (see figure 1).
- Many of the impacts were attributed to the time and burden felt by the individual(s) who attended appointments and took on the key role of coordinating care.

Negative impacts could be reduced by:

1. Having the support of a professional to coordinate care
2. Changing the approach of clinics and appointments (eg where they take place, which professionals/services are available and how they are scheduled)
3. Improving communication between professionals, services and patients (eg by using technology)

Figure 1: Patient and carer experiences of uncoordinated care and their impact



'I think anybody that's in a position like I am should have an appointed care coordinator, an appointed person to go to that pulls everything together, that looks at [the] whole person' [patient and carer, diagnosed rare condition]

'...there are instances where it has been coordinated well by being able to condense all my appointments into one day, which is obviously much kinder on the bank balance... Obviously, it's got a financial cost, but there's a physical cost there, you know, having to go to extra appointments when I needn't have to.' [patient, diagnosed rare condition]

'I would like there to be one central website where I could log on... I could see when he's due to see them next, I could message Consultants... and I could book appointments; maybe I could see his test results and stuff too... to actually access these digitally and online would be fantastic' [carer, undiagnosed rare condition]

### Conclusions

Our findings suggest that uncoordinated care has a negative impact on patients, and their families, in many different ways. Models of care coordination which lessen the time and burden placed on families may be particularly beneficial in reducing these impacts. Findings should influence future service developments (and the evaluation of such developments). In the first instance, findings will inform the [Coordinated Care of Rare Diseases \(CONCORD\) Study](#).



\*Genetic Alliance UK is an alliance of over 100 patient organisations and the national charity working to improve the lives of patients and families affected by genetic conditions

The CONCORD project is funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research Programme (project number 16/11578/1). The views expressed are those of the author(s) and not necessarily those of the NIHR, the NIHR, or the Department of Health and Social Care.

# MAKING THE VOICE OF OUR COMMUNITY HEARD

Our team sat on various committees, steering groups and attended numerous meetings during the year to represent the views of our community:

- Advanced Therapy Medicinal Products – The Landscape, Challenges & Opportunities in Wales
- Presented findings of mitochondrial research priority setting project to the Great Ormond Street Hospital metabolic clinical team
- Association for Responsible Research and Innovation in Genome Editing conference on genome editing
- BIO-Europe
- Breaking Down Barriers Advisory Board
- Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland Expert Advisory Panel (Scotland)
- Co-applicant Delivering Genomic Sequencing In Clinical Practice: A Patient-centred Evaluation Of The New NHS Genomic Medicine Service
- CRISPR Ideas Symposium
- EURORDIS Round Table of Companies Summit on Newborn Screening
- EXPRESS study patient and public involvement group
- Genetic Counsellor Registration Board
- Genetics Evaluation Panel (Scotland)
- Genetics Laboratory Management Meeting (Scotland)
- Genomics Leadership Group (Scotland)
- Medicines Healthcare Regulatory Authority / Office of Life Sciences innovative regulation project interview
- National Genomics Board
- National Institute Health Research Bioresource Steering Committee
- National Patient, Public and Professional Involvement Group (Scotland)
- NHS England - Genomics People and Communities Forum
- NHS England - Genomics Programme Board
- NHS England - Patient and Public Voice Assurance Group
- NHS England - Specialised Commissioning Stakeholder Forum
- NHS England - Women and Children's Programme of Care Board Meeting
- NICE Guideline Committee - Children and young people with disabilities and severe complex needs
- NICE Methods review - working group and task and finish groups
- Office for Rare Conditions (Glasgow) Steering Group
- Office of Health Economics Expert Roundtable: Reform options for the next Voluntary Pricing and Access Scheme
- Preimplantation Genetic Testing Expert Panel (Scotland)
- Public Involvement Network Advisory Group Meeting (Scottish Medicines Consortium)
- Rare Disease Strategic Oversight Group Meeting
- Responding to genetic risk associated with customary consanguineous marriage
- Scotland Rare Disease Strategic Oversight Group
- Scottish Medicines Consortium Patient Involvement Network (Scotland)
- Solve RD Community Engagement Task Force
- Steering Group Meeting
- Wales Rare Disease Oversight and Implementation Group
- Welsh Conservatives 2021 Manifesto Roundtable

# BUILDING GREATER AWARENESS

## Social media

We continue to have a strong social media presence with varied audiences on our different channels. This year the combined reach of our channels grew to 21,000 on Facebook and 41,000 on Twitter and we saw a combined growth of 2,657 new followers on Instagram, and 541 new followers on Linked In. Press included articles in the media planet rare diseases supplement, the New Scientist, Pharma Times, The Sun and Sky News.

## Genomics cafés

Public Genomics Cafés, delivered by Genetic Alliance UK and Wales Gene Park form part of the Genomics Partnership Wales engagement programme. These are free and open to all events which include short, relaxed talks about genomics relating to health and medicine, with guest slots from health professionals, researchers, and those affected by genetic and rare conditions who share personal experiences.

Since May 2020 events have been virtual with themed cafés, online engagement and e-networking. Translation to a virtual platform has been successful, with a positive effect on attendee numbers and broader audiences from across Wales and beyond. Six virtual Genomics Cafés have been held, reaching over 420 people from the public and rare disease community.

In October 2020, a Young People's Genomics Café – primarily aimed at the 16 to 25 age group – was launched. Two events have been held to date, attracting over 225 attendees.



## Annual Rare Disease Patient Network meeting (Wales)

The annual Rare Disease Patient Network meeting was held virtually in December 2020 and was attended by 71 people affected by rare and genetic conditions. The meeting included the launch of Rare Experience 2020 report in Wales.

## UNDIAGNOSED CHILDREN'S DAY

Undiagnosed Children's Day takes place every year on the last Friday of April. Falling this year in the first national lockdown our plans were drastically impacted by the pandemic. We had to cancel our planned events and activities and move everything online at the last minute. Unsure how much engagement we would get as everyone was struggling to adjust to lockdown and shielding, the day ended up providing much needed light relief for the SWAN UK community.

Adapting the hashtag #PaintLockdownPink people took to social media to join in the fun in various ways including dying their hair and beards pink, baking pink cakes and having pink makeovers!

SWAN UK Twitter channel was taken over by our Parent Reps and bloggers who shared their experiences on the day.



# RARE DISEASE DAY 2021

Rare Disease Day takes place at the end of February each year. In 2021, it took place on Sunday 28 February and was celebrated in more than 85 countries around the world. Through our campaign Rare Disease UK, we are the official organiser of the day in the UK.

This year our activities were planned around three aims:

- Utilise the unique opportunity provided by the Covid-19 pandemic to build greater understanding of what it is like to live with a rare disease, and the importance of research to provide answers.
- Unite the UK's rare community to have a strong, amplified voice with which to share their stories and experiences.
- Show our solidarity with the rare disease community in other European countries in light of Brexit.

For the first time, we decided to use the international EURORDIS branding for the day. We ran a six month programme of activities leading up to the day, starting with stakeholder planning events in the Autumn.

The official video, generated from user footage, was reviewed over 5,000 times and accompanied by a story a day published on our website (see pages 19 and 20). We also launched a new TikTok channel and Instagram filter.

## TWITTER

February - 641K impressions  
28 February - 124,173 impressions  
**#RareDiseaseDay 2021 trending**

## FACEBOOK

344 new likes on day  
**#RareDiseaseDay2021 used in 31k posts**

## INSTAGRAM

New followers up 82% from January  
Content interactions up by 972.5%  
**Instagram filter used by 1.1k people, 43.7 impressions**

## TIKTOK

100 followers in first week.  
**#ShowMeYourRare challenge video viewed almost 3K times**



#RAREDISEASEDAY

RARE DISEASE DAY®

RARE DISEASE DAY  
28 FEBRUARY 2021



RARE IS MANY RARE IS STRONG RARE IS PROUD

RARE DISEASE.ORG.UK

## Virtual parliamentary event

In February we hosted the **first ever UK-wide parliamentary event** bringing together Health Ministers, parliamentarians, and health officials from all four nations. The meeting focussed on the implementation of the new UK Rare Diseases Framework in each UK nation. Over 230 people attended the event and Ministers from England, Scotland and Northern Ireland were able to contribute to the meeting. The video of the event of the meeting has since been viewed over 170 times.

*'It's a great conference. Very touching stories.'*  
Lord Bethell

*'I think the event went beautifully. There were some really amazing speakers and I look forward to checking out some of the sections again.'*  
Rhoda Walker, Chair, NIRDP

*'It was a great event. Everyone seemed very engaged and to get the sort of line up you did from all four nations was really very impressive and hopefully reflects the level of interest and focus*

*on the subject.'* Sarah Walker, Senior Consultant Policy and Public Affairs, MAP BIO PHARMA

*'I wanted to say thanks for a really excellent and engaging event this morning. I was genuinely gripped throughout and took lots of notes.'*  
Jessica March, Associate Director for Public Policy & Government Affairs, UK & Ireland

## Rare Disease Day video and stories

The **UK's official video** was produced using footage supplied from the community, with a daily blog post published throughout February to accompany it.

This year we wanted to do something different that highlighted the highs and lows of having a rare condition. We also wanted to have the wider community more involved in the official video for the day so invited people to submit their footage to be included. Over 100 people sent up clips and 28 people also volunteered to share their stories to accompany it - you can read these by clicking on the image below and on pages 19 and 20.



## Rare Disease Day stories

Click on the images below to read the stories



**LAUREN'S STORY**



**LUCY'S STORY**



**ABIGAIL'S STORY**



**WILL'S STORY**



**KIRSTY'S STORY**



**GAIL'S STORY**



**SALLY'S STORY**



**PAM'S STORY**



**MEGAN'S STORY**



**MARY'S STORY**



**CHRISTINE'S STORY**



**MYA'S STORY**



**NUALA'S STORY**



**RAJ'S STORY**



**PHIL'S STORY**



**CHARLOTTE'S STORY**



**LEANNE'S STORY**



**CORRINNE'S STORY**



**DOTTIE'S STORY**



**SARAH'S STORY**



**JESSICA'S STORY**



**JEMMA'S STORY**



**KAT'S STORY**



**FRANCESCA'S STORY**



**SUZANNE'S STORY**



**KAREN'S STORY**



**RACHEL'S STORY**

# RARE REACH FESTIVAL

Launched on Rare Disease Day, the Rare Reach Festival social media awards were a celebration of storytelling in the rare community. Over 100 entries were shortlisted by our judges: Lara Bloom from Ehlers Danlos Society, paralympian Natasha Coates, Cardigan Hughes from Same but Different, Rachel Farrow from Route 73 Consulting and Gavin Jones from Open Health. Click on the images to view the entries.



**PEOPLE'S CHOICE AWARD**  
@jessicamayhall



**BEST STORYTELLING BY A SMALL CHARITY**  
THE APLASTIC ANAEMIA TRUST



**BEST IN SHOW**  
LUKE PEMBROKE'S 'A HAEMOPHILIA GENE THERAPY JOURNEY' (IN THE INDIVIDUAL CAT)



**BEST STORYTELLING BY A VOLUNTARY GROUP**  
TIMOTHY SYNDROME ALLIANCE



**BEST STORYTELLING BY A FAMILY MEMBER**  
ZAINAB @ADNANTHEKALEJU



**BEST STORYTELLING BY A YOUNG PERSON**  
ROBBIE @MEMYSELFANDBEHCETS



**BEST STORYTELLING BY A LARGE CHARITY OR INDUSTRY**  
NERVE TUMOURS UK



**BEST STORYTELLING BY AN INDIVIDUAL**  
LUKE PEMBROKE

# BUILDING OUR COMMUNITY

## WORKING WITH OUR MEMBERS

We are proud to be the UK's largest alliance of organisations supporting the genetic, rare and undiagnosed community. Made up of over 200 members ranging from the large to the tiny, we welcomed 12 new members this year (see page 23). Over 50% of our members are small charities or voluntary led and represent a range of conditions from the rare to the ultra rare. We also have a number of umbrella organisations or those working within our community to support or upskill others.

Covid-19 and the move to virtual working and events has had a positive impact on our relationship with our member organisations encouraging a more interactive and dynamic interaction. This has given us a greater understanding of the issues many of our members, especially the smaller ones, are facing and how we can support them. Using the weekly community check-in we have hosted discussions on diverse topics to aid sharing tips and good practice including running virtual meetings, collaborating with industry, pairing with MSC student for research and supporting mental wellbeing. We also hosted sessions on the NICE methods review, the new genomic medicine service and the new Medics for Rare Diseases Rare Diseases 101 platform.

Our closer relationship with our members has been mirrored in taking a more proactive approach to engaging with them on our social media channels to help amplify their voice and showcase their work. We helped promote numerous awareness campaigns and during the run-up to Rare Disease Day we provided branded assets for 25 organisations. In partnerships with Findacure, we also ran three social media workshops to support organisations to produce their own graphics.

Despite the pandemic we have continued to offer information and support to individual members on a range of topics including access to medicine and new born screening. We also responded to over 1,000 emails and phone calls asking for information on a topics including insurance, access to genetic testing, PGD and vaccines and rare conditions.

 **Genetic Alliance UK** @GeneticAll\_UK · Oct 12, 2020  
"Terminating a wanted pregnancy for medical reasons is already a "taboo within the taboo" of baby loss, but the genetic factor adds another layer of complexity ...". Read more from our member @ARCantenatal as part of #babylossawarenessweek: [ow.ly/FHik50BNaFe](https://ow.ly/FHik50BNaFe)  
#BLAW



 **Genetic Alliance UK** @GeneticAll\_UK · Dec 15, 2020  
We're happy to have helped @ProfPWC with #OurHumanCondition project. His work, shown at @OXO and @southbankcentre explores the lives and relationships of #siblings with #genetic conditions. For stunning #photography and #storytelling, visit his website: [ow.ly/B5KU50CGTVS](https://ow.ly/B5KU50CGTVS)



 **Genetic Alliance UK** @GeneticAll\_UK · Dec 18, 2020  
Learn skills to build your #emotional #resilience, help you manage #difficult conversations and better support your community. In January we're offering a 12 week programme in partnership with @RareMindsCIC. More details and sign up here: [ow.ly/FCB360CL6Xc](https://ow.ly/FCB360CL6Xc)



 **Genetic Alliance UK** @GeneticAll\_UK · Feb 17  
Do you want your logo on the #RareDiseaseDay2021 graphics like the one below? 🙌 Get in touch with us and we will make it happen!



# NEW MEMBERS

Genetic Alliance UK is the largest alliance of organisations supporting people with genetic, rare and undiagnosed conditions in the UK. Our members and the people they support are at the heart of everything we do. We were delighted to welcome 12 new members this year.



Syngap Research Fund



Neuroendocrine Cancer UK



Cure Myotonic Dystrophy UK



The Schinzel-Giedion Syndrome Foundation



Cystinosis Foundation UK



NF2 Biosolutions



Hadiza foundation



Northern Ireland Rare Disease Partnership



PIP-UK



SarcoidosisUK



Medics for Rare Diseases



Hope for Hasti

# RARE RESOURCES – SCOTLAND

Rare Resources (Scotland) is a project designed to address the gaps in information and support provided to people living with, or caring for a person living with, a rare condition in Scotland.

Through co-production with our community we have developed the **Rare Resources Toolkit** - a downloadable, toolkit of information for families in Scotland who have recently received a diagnosis of a genetic or rare condition.

The toolkit contains a wide range of general information on genetic, rare and undiagnosed conditions as well as information on how to access reliable information, care and support in Scotland.

In 2021, we have expanded the toolkit to include a **short leaflet for adults** receiving a diagnosis of a rare condition. We have also developed a **helpful leaflet for health professionals**, designed by people living with a rare condition, which explains how they wish to be treated and where health professionals can access further information and training.

Due to the Covid-19 pandemic, plans to deliver a Rare Resources Roadshow in Scotland were postponed. The Roadshow was intended to feature a series of informal information sessions for people living with a rare, genetic condition, delivered in collaboration with local support, and healthcare services in six locations across Scotland.

Whilst the Roadshow could not take place, as part of the project, to we delivered a series of online events, activities to offer families support during the lockdown periods.

Events included:

- A virtual mental health support session delivered by Breathing Space
- Brew and Blether sessions (six informal coffee-morning sessions for people to share their experiences of lockdown - attendees were offered a mug, biscuit and tea bags to be posted to them)
- A Q and A session with Scottish Government's Vaccination Team

Over 40 people attended these events and we also offered 30 'boredom packs' for children living with rare, genetic and undiagnosed conditions during lockdown. The boredom packs contained fun craft activities for children.

## 3.2 What does NHS Scotland provide for children?



### NHS Scotland is responsible for providing care for children with genetic, rare or undiagnosed conditions in Scotland.

This includes GP appointments, appointments with specialist clinicians, visits to NHS regional genetic centres and a wide variety of other services.

NHS Scotland also commissions specialist services for rare conditions, including services for genetic and undiagnosed conditions.

The services available for genetic, rare or undiagnosed conditions are varied and wide ranging.

The National Services Division (NSD) is responsible for the national commissioning for very specialist services that cannot be provided at a local or regional level.

These services are generally concerned with the diagnosis and/or treatment of rare conditions.

The diversity of rare conditions and the specialist knowledge required to diagnose and treat them mean that it is not always possible to have a service for a rare condition available near to home.

Sometimes a specialist can't be found in Scotland and a child will have to travel to another part of the UK to access specialist care.

National Service Division is responsible for the commissioning of specialist services from elsewhere in the UK and ensuring that Scottish patients are able to access them.

There are also National Managed Clinical Networks (NMCNs) that link together health professionals, patients, third sector organisations and other partners to improve access to services for patients who often have complex or rare conditions.

For example, the Children with Exceptional Healthcare Needs NMCN exists to strengthen specialist services for children in Scotland with complex and exceptional healthcare needs.



**RARE**  
resources  
SCOTLAND



# 1 Genetic, rare and undiagnosed conditions explained

# SWAN UK

It was a difficult year for our SWAN UK families as they struggled to cope with the pandemic, shielding and lack of clear information about the risk of Covid-19 for their families.

Welcoming 195 members, this was a drop compared to previous years, and caused by the impact of Covid-19 on our usual outreach channels. We now support 3,476 members across the UK.

## Family events

With all of our usual regional events cancelled, we quickly put a new programme of support in place including virtual drop ins, kids quizzes and discos and a Christmas sing and sign event. We also ran targeted outreach and support to SWAN UK dads including sending out care packages and running a comedy night.

‘Guy’s, for those who joined the Comedy Night and those who stayed on afterwards, what a great night and a BIG SHOUT OUT to the organisers, thank you.’ SWAN UK dad

‘Nice surprise with the bag of tricks, thank you. The chocolate was lovely and my youngest loved the Whoopi cushion....They’ve been in stitches with it before bath time...been the best fun all lockdown.’ SWAN UK dad

## Emotional support

Recognising the additional emotional stress of Covid-19, we also piloted running weekly group counselling sessions for 23 parents.

‘I found it really helpful to connect with others who I could speak with freely without judgement. I felt able to talk about things that I hadn’t had the opportunity to ‘offload’ in a safe and supportive space.’ SWAN UK member

## Parent Reps and the SWAN UK Council

Our usual volunteering programme has been paused during the pandemic but we have continued to meet virtually with our Parent Reps and SWAN UK Council members. They have helped us to continue to monitor the impact of Covid-19 on the undiagnosed community and how we can respond.

## SWAN UK - Cymru

We were delighted this year to successfully be awarded a three year grant from the National Lottery in Wales to expand our SWAN UK support network in Wales. Our new bi-lingual outreach worker joined us in January and we officially launched the project on St David’s Day with our first ever bi-lingual newsletter. We also have new bi-lingual social media channels and are working on a Rare Resources: Cymru toolkit.



**LOUISE JAMES, CHAIR, SWAN UK COUNCIL**

# GWANWYN 2021

Cylchlythyr Chwarterol

## SPRING 2021

Quarterly Newsletter



**SWAN** UK

syndromes without a name

26

# BUILDING OUR ORGANISATION

As for many charities, the pandemic was a disruptive event that forced us to respond quickly and proactively to ensure our future. The financial situation at the end of the previous year meant that the team was primed to react quickly to the financial risks that the pandemic brought. We moved quickly to virtual working and made the difficult decision to furlough the majority of our staff team over the summer. The majority of our funders also reacted quickly to the urgent need to deliver a service to our community. The combination of our quick reaction and the support of our funders has allowed us to build back our organisational reserves despite the challenging circumstances.

Our organisation has now embraced the opportunities of virtual working and working from home. Those few team members for whom home working is not possible have had necessary adjustments made, with desk space rented as needed.

We undertook a full organisational and fundraising review exploring where we could make savings, work more effectively and how to maximise our fundraising capacity. As a result of the restructure we merged all our membership support activities with our work with the SWAN UK community into a new Engagement and Support department. This resulted in three new hybrid roles and some empty posts being made redundant. This allowed us to streamline our staff team to ensure we are working in the most cost effective way.

Our work with an external fundraising consultant identified areas of strength and areas of potential growth but the full execution of these plans were disrupted by the pandemic. The strength and dedication of our team however ensured that despite having very limited team fundraising capacity, we successfully gained funding for our Covid-19 relief programme, and a new grant from the National Lottery to develop a SWAN UK network in Wales. At the end of 2020-21 we recruited a new Director of Fundraising who developed a new three year fundraising strategy.

At the time of writing we are pleased to note that the average length of service of the current team is more than five years, and that eight out of the eighteen of the team have been with us longer than this time. The commitment of our staff, combined with their high levels of expertise, fosters a strong institutional memory - the latter of which we are also continuing to embed in new processes to reduce the potential risk associated with any future staff departures. The stability of the team, and strong working relationships between team members, allowed a smooth transition to virtual working and maintaining our team culture. It is also thanks to their dedication and hard work that we are ending this year in a much stronger financial position than the previous year.



**MEMBERS OF THE GENETIC ALLIANCE UK TEAM**

# THE COMING YEAR

This has been a transitional year for Genetic Alliance UK in many ways. As we move forward into 2021/22 and beyond our focus will be on developing a sustainable and responsive organisation. Responsive to the changing national context as we move beyond the pandemic, responsive to a post Brexit world and most importantly, responsive to the needs of the community we serve - everyone affected by a genetic, rare or undiagnosed condition.

With our mid-point strategy review due in the Autumn, we will take this opportunity to reflect on our many successes over the last few years, but also be open and honest about the areas where we will have more work to do. As the UK's largest alliance of rare genetic organisations, we have a responsibility to ensure that all voices are heard. So with a spirit of collaboration at the heart of everything we do, we will focus on strengthening existing relationships with our members and key stakeholders whilst also forging new, and repairing lapsed ones. We will strive to give our members the best possible platform to achieve their aims, including by introducing new member benefits to amplify their voice.

As we continue to welcome new members we will particularly focus on ensuring the voice of people living with rare conditions is as diverse as possible. During 2021/22 we will undertake a full diversity and inclusion review of our internal and external working practices and commit to taking action to make our organisation fully representative of the community we serve.

Following the publication of the UK Rare Diseases Framework at the beginning of 2021, this year will be crucial to maximising the potential of this policy opportunity. We will put significant resources into ensuring that there are as many voices of people living with genetic, rare and undiagnosed conditions feeding into the development of the four nations' action plans as possible. This will be done by empowering our membership to take up formal representative roles and ensuring our team members are connected to these roles, and also by empowering our broadest networks to feed into the process. We will support all these representatives and provide a forum for them to

exchange information and support each other. It is crucial that we carry the thread of inclusion through to this element of our work so that the voice of our community in this process is diverse and representative.

The Framework has the potential to bring together many of our policy priorities including diagnosis, screening and access to medicines for rare conditions. We will continue to engage closely with the development of genomic medicine across the UK, and in the myriad expected opportunities to improve access to medicines for rare conditions that will arise from the Innovative Licensing and Access Pathway, the Innovative Medicines Fund and the NICE Methods and Process Review.

To an extent our strong performance in fundraising in the previous year was related to a quick reaction to the Covid-19 need, and the novelty of the situations charities in our sector faced. The funding environment is still constrained by the impacts of the pandemic, and the challenges our community faces continue to be considerable. This means income generation may be more difficult in this year than the previous. We intend to broaden our income streams as much as possible, broadening our relationships with corporate funders while maintaining our independence, expanding our approach with trusts and foundations, while maintaining the growth of our community fundraising activities. We will also explore and encourage collaborative and partnership funding to ensure the sustainability of the whole community.

We have no immediate plans to return to a fully staffed office in the near future and instead will utilise a hybrid approach with some staff members co-located in shared workspace, while the majority of the team work from home. Once the team is fully-vaccinated, we will consider how we can regularly bring the team together to foster and maintain the sense of team spirit that was a key element of our previous office-based environment.

Having had a transitional year, our focus is now on laying the groundwork for a sustainable future, which we will set out in detail in our upcoming strategy review.

# TREASURER'S LETTER AND FINANCIAL REVIEW

31 March 2021

Thank you to all our members and funders. You have ensured that the work outlined in this report could continue at such a challenging time for the people we support.

## REVIEW OF THE FINANCIAL POSITION INCOME

The results for the year are set out in the statement of financial activities on page 37. The total income for year was £939,440 (£804,434 in 2020).

The increase in income is a significant achievement in a challenging fundraising environment. It was driven principally by a greater level of funding from our supporters as shown in Note 2 of the Financial Statements. We were also able to access support from the Government's Job Retention Scheme as the pandemic continued to disrupt our operations.

### Expenditure

Total expenditure for the year was £808,907 (£1,005,274 in 2020).

The decrease in the spending is principally due to a marked fall in the funding secured for specific projects in support of our charitable activities and the disruption caused by the Covid-19 crisis.

The organisation also took a series of cost control measures during the year as part of the plan to ensure a more resilient financial position.

### Surplus/Deficit

Our final financial position for the year across all funds is a surplus of £130,533 (deficit of £200,840 in 2020). The majority of the surplus is driven by a surplus on our unrestricted funds of £115,952 (compared to a deficit of £142,731 in 2020).

This reflects the changed income mix during the period and reduction in restricted project funding received.

### Reserves Policy

Total reserves at the end of the financial year are £199,864 (£69,331 in 2020).

This is made up of restricted reserves of £39,134 (£24,513 in 2020) and unrestricted reserves of £160,730 (£44,778 in 2020).

The small increase in restricted reserves is due to slightly higher income than spending on specific projects as detailed in Note 18.

The increase in unrestricted reserves is due to the success of income raising efforts in the period, a reduction in spending as noted above and thoughtful cost control measures.

The Trustees have set a target in the medium term to hold unrestricted reserves that equate to approximately six months of unrestricted expenditure. Our current level of reserves has significantly increased over the year and is now approximately four months by this measure. This is a positive development, however, the Board and Executive Team are clear that income generation and cost control measures need to continue to ensure that we can maintain and maximise our impact in the years ahead.

### Conclusion

The financial year ended 31 March 2021 was a challenging one for Genetic Alliance UK from an operational and financial perspective. However, at the year end the financial position shows a notable improvement from that seen 12 months prior.

At the time of writing, Covid-19 remains the dominant issue likely to impact during the current financial year, however, the Executive Team have demonstrated their ability to lead and manage in a challenging environment.

In this uncertain time, financial risk still remains and the year ahead will require a renewed focus on fundraising and continued cost consciousness. Genetic Alliance UK starts the period with stronger financial foundations and we are pleased that the Auditors have endorsed the view that Genetic Alliance UK remains a going concern and we will work to ensure that it continues to be there for all those who need.



**D A Ramsden**

Treasurer, Board of Trustees

# REFERENCE AND ADMINISTRATIVE DETAIL

## Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

## Registered company number

05772999

## Registered charity numbers

1114195 & SC039299

## Registered office

During the period of this report: Third Floor, 86-90 Paul Street London, EC24 4NE  
Currently: Creative Works, 7 Blackhorse Lane, London, E17 6DS

## Trustees

Ms S Butterworth  
Ms G J Clark  
Ms P A Farrant  
Ms S J Hunt  
Dr C Lewis  
Mr N McClements  
Ms S J Millman  
Mrs E Porterfield  
Mr D A Ramsden  
Ms S Walsh  
Mrs J S Wootton  
Dr S Wynn

## Board observer

Robin Nott

## Chief Executive Officer

Dr Jayne Spink (until 31 March 2021)  
Lauren Roberts and Nick Meade (appointed as Joint Interim Chief Executives 1 April 2021)

## Management team

Dr Amy Hunter, Nick Meade, Lauren Roberts

## Auditors

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

## Management accountant

Fiona Bevan Financial Management

## Bankers

CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Mailing, 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](http://geneticalliance.org.uk)

## Facebook

GeneticAllianceUK

## Twitter

GeneticAll\_UK

## Instagram

GeneticAllianceUK

## LinkedIn

Genetic Alliance UK

# 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

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

## Governance and organisational management

Trustees met five times in the year ending 31 March 2021, where they reviewed the charity's performance and determined and approved operating plans and budget. Trustees delegate certain powers in connection with the charity's management, remuneration (related to responsibility and market comparisons) and administration to the Finance and Governance (F&G) committee, which met four times in the year. The Finance and Governance Committee provides detailed oversight and advice to the Board of Trustees in relation to financial management, financial viability, risk management and governance. The Finance and Governance 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 Officer and Directors of Genetic Alliance UK are ex officio.

## 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. A new Covid-19 risk register has also been produced. All risks are reviewed at each meeting of the Board of Trustees and by the Finance and Governance Committee.

## Fundraising

Genetic Alliance UK undertakes most of its fundraising activities in-house but used a consultant solely for the purposes of large grant applications. Genetic Alliance UK is registered with the Fundraising Regulator and have adhered 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.

## Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

# TRUSTEE RESPONSIBILITY

The trustees (who are also the directors of Genetic Alliance UK Ltd for the purposes 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 judgements 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 11 August 2021 and signed on the Board's behalf by:



**Elizabeth Porterfield**,  
Chair, Board of Trustees

# INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF GENETIC ALLIANCE UK

## Opinion

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2021 set out on pages 37 to 53 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 2021, 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 33 the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

## **Auditor's responsibilities for the audit of the financial statements**

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

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

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

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

We focussed on laws and regulations which could give rise to a material misstatement in the financial statements, including, but not limited to, the Companies Act 2006.

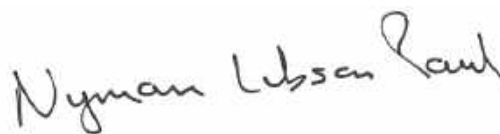
Our tests included agreeing the financial statement disclosures to underlying supporting documentation and enquiries with management. There are inherent limitations in the audit procedures described above and, the further removed non-compliance with laws and regulations is from the events and transactions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

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

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: [www.frc.org.uk/auditorsresponsibilities](http://www.frc.org.uk/auditorsresponsibilities). This description forms part of our auditor's report.

## Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



**Jennifer Pope** (senior statutory auditor)

for and on behalf of  
Nyman Libson Paul LLP  
Chartered Accountants  
Registered Auditors  
124 Finchley Road  
London  
NW3 5JS

Date: 11 August 2021

# STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

Year ended 31 March 2021

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £	Total Funds 2020 £ (Restated)
<b>Income from:</b>					
Donations and legacies	2	584,410	349,473	933,883	761,400
Charitable activities	3	5,557	-	5,557	42,134
Investments			-	-	900
<b>Total income</b>		<b>589,967</b>	<b>349,473</b>	<b>939,440</b>	<b>804,434</b>
<b>Expenditure on:</b>					
Raising funds	4	105,444	-	105,444	117,812
Charitable activities	5	368,613	334,850	703,463	887,462
<b>Total expenditure</b>		<b>474,057</b>	<b>334,850</b>	<b>808,907</b>	<b>1,005,274</b>
<b>Net income/(expenditure)</b>	<b>8</b>	<b>115,910</b>	<b>14,623</b>	<b>130,533</b>	<b>(200,840)</b>
<b>Transfers between funds</b>	<b>18</b>	<b>42</b>	<b>(42)</b>	<b>-</b>	<b>-</b>
<b>Net movement in funds</b>		<b>115,952</b>	<b>14,581</b>	<b>130,533</b>	<b>(200,840)</b>
<b>Total funds at start of year</b>	<b>18</b>	<b>44,778</b>	<b>24,553</b>	<b>69,331</b>	<b>270,171</b>
<b>Total funds at end of year</b>	<b>18</b>	<b>160,730</b>	<b>39,134</b>	<b>199,864</b>	<b>69,331</b>

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 40 to 53 form part of the these financial statements  
See note 11 for fund-accounting comparative figures

# BALANCE SHEET

## Year ended 31 March 2021

Company number: 05772999

	Note	2021 £	2020 £
<b>Current assets</b>			
Debtors	12	126,373	146,855
Cash at bank and in hand		239,896	112,055
		<u>366,269</u>	<u>258,910</u>
<b>Liabilities</b>			
Creditors : amounts falling due within one year	13	(166,405)	(189,579)
<b>Net current assets</b>		<u>199,864</u>	<u>69,331</u>
<b>Total assets less current liabilities</b>		<u>199,864</u>	<u>69,331</u>
<b>Net assets</b>		<u><u>199,864</u></u>	<u><u>69,331</u></u>
<b>FUNDS</b>			
<b>Unrestricted funds</b>			
General funds	19	62,409	44,778
Designated funds	19	98,321	-
<b>Restricted funds</b>	19	39,134	24,553
<b>Total funds</b>		<u><u>199,864</u></u>	<u><u>69,331</u></u>

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

These financial statements were approved by the Trustees on 11 August 2021 and are signed on their behalf by:



Liz Porterfield  
Chair of Trustees

**The notes on pages 40 to 53 form part of the these financial statements**

# CASH FLOW STATEMENT

Year ended 31 March 2021

	Note	2021 £	2020 £
<b>Net cash inflow from operating activities</b>	<b>15</b>	127,841	(183,259)
<b>Non-operational cash flows:</b>			
<b>Investing activities</b>			
Investment income		-	900
		<hr/>	<hr/>
		-	900
<b>Net cash inflow/(outflow) for the year</b>	<b>16</b>	<hr/> <hr/>	<hr/> <hr/>
		127,841	(182,359)

## 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

The notes on pages 40 to 53 form part of the these financial statements

# NOTES TO THE FINANCIAL STATEMENTS

Year ended 31 March 2021

## 1 Accounting policies

### Accounting convention

The financial statements have been prepared under the historical cost convention, and in accordance with the companies Act 2006, the Charities Act 2011, the Financial Reporting Standard 102 (FRS102) and the requirements of the Charities Statement of Recommended Practice based thereon.

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

### Going concern

Following significant forward planning, fundraising efforts and other initiatives undertaken in early 2020, when the Charity was facing a challenging future, the Trustees and Executive have been able to reverse the financial decline and are able to report an unrestricted fund surplus for the year ended 31 March 2021 of £115,952, compared to a deficit for the previous year of £144,667. As a result of this outturn the Charity's unrestricted free reserves (general and designated funds) stand at £160,730 as at 31 March 2021, providing a solid base from which to continue to build reserves.

The charity did face additional challenges in the year arising from the economic and other consequences of the Covid-19 pandemic but any adverse effects were countered by the careful planning and budgeting undertaken.

The Trustees have now reviewed the current circumstances of the Charity and updated budgets, forecasts and projections for the next 12 months have been prepared. Prudent assumptions indicate that the Charity will earn a small surplus for the year ending 31 March 2022 and that adequate liquid resources will continue to be available to fund the activities of the charity for the foreseeable future.

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

### Income

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

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

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

Membership income is accounted for as receivable.

Investment income is included on a receivable basis.

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

## 1 Accounting policies (*continued*)

### **Expenditure**

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

### ***Raising funds***

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

### ***Charitable Activities***

Grants awarded are allocated to charitable activities.

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

### ***Governance costs***

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

### ***Allocation and apportionment costs***

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

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

### **Pension costs and other post-retirement benefits**

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

### **Fixed assets**

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

### **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.

### **Cash**

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

## 1 Accounting policies (continued)

### 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

	<b>Unrestricted Funds</b>	<b>Restricted Funds</b>	<b>Total Funds 2021</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Donations from supporters	397,745	185,235	582,980
Wellcome Trust	50,590	-	50,590
University College London	-	44,841	44,841
The Corra Foundation	-	36,805	36,805
National Lottery funding	-	25,907	25,907
City Bridge Trust	-	25,700	25,700
Edward Gostling	4,994	-	4,994
<i>Grants from Government</i>			
National Lottery funding	-	20,026	20,026
Scottish Government	-	9,821	9,821
Covid Job Retention Scheme fund	67,202	-	67,202
Other grants received	1,000	-	1,000
<i>Donations through fundraising:</i>			
Community fundraising	7,552	-	7,552
Online donations	55,327	1,138	56,465
	<b>584,410</b>	<b>349,473</b>	<b>933,883</b>

## 2 Income from donations and legacies (continued)

### Prior year

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2020 £</b> (Restated)
Donations from supporters	58,564	241,450	300,014
Wellcome Foundation	95,000	-	95,000
University College London	-	64,563	64,563
Sheffield Hallam University	-	9,907	9,907
Other grants	-	85,000	85,000
Smaller grants	18,941	81,932	100,873
<i>Grants from Government</i>			
Department of Health and Social Care	20,000	-	20,000
Public Health England	25,000	-	25,000
<i>Donations through fundraising:</i>			
Community fundraising	13,039	-	13,039
Online donations	48,004	-	48,004
	<u>278,548</u>	<u>482,852</u>	<u>761,400</u>

## 3 Income from: Charitable activities

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2021 £</b>
Consultancy work	5,557	-	5,557
	<u>5,557</u>	<u>-</u>	<u>5,557</u>

### Prior year

	<b>Unrestricted Funds £</b>	<b>Restricted Funds £</b>	<b>Total Funds 2020 £</b> (Restated)
HFEA work	12,519	-	12,519
Conference receipts	8,890	-	8,890
Industry supporters	20,725	-	20,725
	<u>42,134</u>	<u>-</u>	<u>42,134</u>

#### 4 Expenditure on: Raising funds

	<b>Total Funds 2021 £</b>	<b>Total Funds 2020 £</b> (Restated)
Staff costs, including consultancy work	62,938	34,373
Fees	2,990	-
Other direct costs	44	5,403
Support costs (Note 6)	39,472	78,036
	<u>105,444</u>	<u>117,812</u>

#### 5 Expenditure on Charitable activities

	<b>Direct Costs £</b>	<b>Support Costs (Note 6) £</b>	<b>Total Funds 2021 £</b>
Membership and Engagement	110,002	114,597	224,599
Policy work	122,778	194,119	316,897
Research	71,233	90,734	161,967
	<u>304,013</u>	<u>399,450</u>	<u>703,463</u>
<b>Prior year</b>			
	<b>Direct Costs £</b>	<b>Support Costs (Note 6) £</b>	<b>Total Funds 2020 £</b> (Restated)
Membership and Engagement	274,218	78,522	352,740
Policy work	257,935	127,362	385,297
Research	85,474	63,951	149,425
	<u>617,627</u>	<u>269,835</u>	<u>887,462</u>

£244,779 of the above support costs in notes 4 and 5 and £229,278 of direct costs relate to unrestricted funds spent during the year. £194,143 of support costs and £140,707 of direct costs relate to restricted funds spent during the year.

£254,271 of the above support costs in notes 4 and 5 and £209,313 of direct costs relate to unrestricted funds spent during the prior year. £93,600 of support costs and £448,090 of direct costs relates to restricted funds spent during the prior year.

## 6 Support costs

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

	<b>Raising Funds</b>	<b>Charitable Activities</b>	<b>Total 2021</b>
	<b>£</b>	<b>£</b>	<b>£</b>
Staff costs	32,455	271,435	303,890
Communications	1,637	13,691	15,328
Office and admin costs	5,380	44,999	50,379
Travel	-	231	231
Finance costs	-	889	889
Professional fees	-	58,005	58,005
Governance costs (Note 7)	-	10,200	10,200
	<u>39,472</u>	<u>399,450</u>	<u>438,922</u>

### Prior year

	<b>Raising Funds</b>	<b>Charitable Activities</b>	<b>Total 2020</b>
	<b>£</b>	<b>£</b>	<b>£</b>
			(Restated)
Staff costs	34,154	127,983	162,137
Office and admin costs	43,882	97,203	141,085
Travel	-	28	28
Finance costs	-	971	971
Professional fees	-	36,407	36,407
Governance costs (Note 7)	-	7,243	7,243
	<u>78,036</u>	<u>269,835</u>	<u>347,871</u>

## 7 Governance costs

	<b>Total Funds 2021</b>	Total Funds 2020
	<b>£</b>	£
Auditor's fees - for audit services	7,200	7,200
Accounts review	3,000	-
Trustee expenses	-	43
	<u>10,200</u>	<u>7,243</u>

## 8 Net income/(expenditure) for the year

This is stated after charging:

	<b>2021</b>	2020
	<b>£</b>	£
Auditor's remuneration - for audit services	7,200	7,200
Trustees' travel, meeting and training expenses	-	43
	<u>7,200</u>	<u>7,243</u>

No Trustee received any remuneration during the year.

## 9 Staff costs and numbers

The aggregate payroll costs were:

	<b>2021</b>	2020
	<b>£</b>	£
Wages & salaries	483,459	528,270
Social security costs	47,496	49,269
Pension contributions	33,650	37,209
Redundancy costs	33,901	-
	<u>598,506</u>	<u>614,748</u>

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

	<b>2021</b>	2020
Between £60,001 and £70,000	-	1
Between £70,001 and £80,000	<u>1</u>	<u>-</u>

The average weekly number of employees during the year was 17 (2020: 22), 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 £234,821 (2020: £246,460).

## 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 2020	Unrestricted Funds £ (Restated)	Restricted Funds £ (Restated)	Total Funds 2020 £ (Restated)
<b>Income from:</b>			
Donations and legacies	278,548	482,852	761,400
Charitable activities	42,134	-	42,134
Investments	900	-	900
<b>Total income</b>	<u>321,582</u>	<u>482,852</u>	<u>804,434</u>
<b>Expenditure on:</b>			
Raising funds	116,888	924	117,812
Charitable activities	346,696	540,766	887,462
<b>Total expenditure</b>	<u>463,584</u>	<u>541,690</u>	<u>1,005,274</u>
<b>Net income/(expenditure)</b>	(142,002)	(58,838)	(200,840)
<b>Transfers between funds</b>	(2,665)	2,665	-
<b>Net movement in funds</b>	(144,667)	(56,173)	(200,840)
<b>Total funds at start of year</b>	189,445	80,726	270,171
<b>Total funds at end of year</b>	<u>44,778</u>	<u>24,553</u>	<u>69,331</u>

During the current year, the trustees reviewed the classification of income and expenditure, and reallocated the total amounts to better reflect the nature of the transactions in the light of the requirements of the Statement of Recommended Practice.

## 12 Debtors

	2021 £	2020 £
<b>Due in less than one year:</b>		
Trade debtors	125,729	66,665
Prepayments and accrued income	-	62,390
Other debtors	644	17,800
	<u>126,373</u>	<u>146,855</u>

### 13 Creditors: amounts falling due within one year

	2021	2020
	£	£
Trade creditors	7,551	87,442
Social security and other taxes	11,248	27,054
Other creditors	3,446	4,851
Accruals and deferred income	144,160	70,232
	<u>166,405</u>	<u>189,579</u>

### 14 Operating lease commitments

At 31 March 2021, the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2021	2020
	Equipment	
	£	£
Expiry Date:		
Not later than one year:	5,171	5,839
Later than one year, and not later than 5 years:	-	6,464
	<u>5,171</u>	<u>12,303</u>

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

	2021	2020
	£	£
Statement of Financial Activities: Net movement in funds	130,533	(200,840)
Investment income	-	(900)
(Decrease)/increase in creditors: current liabilities	(23,174)	86,235
Decrease / (increase) in debtors	20,482	(67,754)
<b>Net cash inflow/(outflow) from operating activities</b>	<u>127,841</u>	<u>(183,259)</u>

## 16 Analysis of changes in cash during the year

	<b>Note</b>	<b>2021</b> £	2020 £	<b>Change</b> £
Cash at bank and in hand		239,896	112,055	127,841
		<b>2020</b> £	2019 £	<b>Change</b> £
Cash at bank and in hand		112,055	294,414	(182,359)

## 17 Analysis of changes in net debt

	<b>1 April</b> <b>2020</b> £	<b>Cashflow</b> <b>Movements</b> £	<b>31 March</b> <b>2021</b> £
Cash at bank and in hand	112,055	127,841	239,896
	<u>112,055</u>	<u>127,841</u>	<u>239,896</u>
Prior year	<b>1 April</b> <b>2019</b> £	<b>Cashflow</b> <b>Movements</b> £	<b>31 March</b> <b>2020</b> £
Cash at bank and in hand	294,414	(182,359)	112,055
	<u>294,414</u>	<u>(182,359)</u>	<u>112,055</u>

## 18 Movement in Funds

For the year ended 31 March 2021

	At 1 April 2020 £	Income £	Expenditure £	Transfers £	At 31 March 2021 £
<b>Restricted funds</b>					
Rare Disease Day 2018	28	-	(28)	-	-
Scotland Boost	-	9,821	(8,512)	-	1,309
Action for Access	13,047	10,000	(4,646)	-	18,401
Concord	1,061	44,841	(45,902)	-	-
RD PSPs	6,881	-	(1,439)	-	5,442
SWAN UK: Dads' Summit	-	6,364	(6,364)	-	-
SWAN UK Wales	-	25,907	(15,979)	-	9,928
Genomic Data	42	-	-	(42)	-
Building Rare Resilience	-	20,026	(20,026)	-	-
Talking about Gene Therapy	3,494	10,000	(9,440)	-	4,054
Patient survey	-	38,600	(38,600)	-	-
Rare Resources	-	2,846	(2,846)	-	-
Covid-19	-	158,505	(158,505)	-	-
Rare Disease Day	-	22,563	(22,563)	-	-
	<u>24,553</u>	<u>349,473</u>	<u>(334,850)</u>	<u>(42)</u>	<u>39,134</u>
<b>Unrestricted funds</b>					
General funds	44,778	182,069	(162,607)	(1,831)	62,409
<b>Designated funds</b>					
Rare Disease Day	-	60,000	(25,133)	-	34,867
Rare Disease UK General Donations	-	290,748	(227,294)	-	63,454
SWAN UK: General Donations	-	57,150	(59,023)	1,873	-
	<u>44,778</u>	<u>589,967</u>	<u>(474,057)</u>	<u>42</u>	<u>160,730</u>
<b>Total funds</b>	<u>69,331</u>	<u>939,440</u>	<u>(808,907)</u>	<u>-</u>	<u>199,864</u>

### Fund descriptions

#### Restricted funds

**Rare Disease Day** - funds received to help with the costs of putting on our annual Rare Disease Day

**Scotland Boost** - funds received for the dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions.

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

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

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

## 18 Movement in funds (*continued*)

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

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

**Genomic Data** - funds were received to complete work to understand the attitudes of people living with genetic, rare and undiagnosed conditions and storage of their data.

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

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

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

**Rare Resources** - funds are restricted to the development and dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions

### **Designated funds**

**Rare Disease Day** - funds were set aside by the trustees to support awareness of rare conditions. They will be spent on awareness raising activities.

**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.

## 18 Movement in funds (continued)

For the year ended 31 March 2020

	At 1 April 2019 £	Income £	Expenditure £	Transfers £	At 31 March 2020 £
<b>Restricted funds</b>					
SWAN UK: BLF England	21,141	21,141	(42,282)	-	-
Rare Disease UK	-	224,950	(224,950)	-	-
Rare Disease Day 2018	20,000	73,750	(93,722)	-	28
Scotland Boost	-	-	(117)	117	-
Action for Access	10,000	54,000	(50,953)	-	13,047
Solve-RD	3,350	9,906	(15,192)	1,936	-
Concord	-	64,563	(63,502)	-	1,061
RD PSPs	26,235	5,000	(24,354)	-	6,881
SWAN UK: Dads' Summit	-	-	(612)	612	-
Genomic Data	-	3,042	(3,000)	-	42
Talking about Gene Therapy	-	26,500	(23,006)	-	3,494
	80,726	482,852	(541,690)	2,665	24,553
<b>Unrestricted funds</b>					
General funds	90,312	222,524	(266,121)	(1,937)	44,778
Rare Disease Day	-	16,630	(16,630)	-	-
Rare Disease UK General Donations	18,072	16,761	(34,716)	(117)	-
SWAN UK: General Donations	81,061	65,667	(146,117)	(611)	-
	189,445	321,582	(463,584)	(2,665)	44,778
<b>Total funds</b>	270,171	804,434	(1,005,274)	-	69,331

## 19 Analysis of net assets between funds

	Restricted Funds £	Unrestricted Designated Funds £	Unrestricted General Funds £	Total £
<b>As at 31 March 2021</b>				
Bank and cash	39,134	98,321	102,441	239,896
Other net assets	-	-	(40,032)	(40,032)
	39,134	98,321	62,409	199,864

## 19 Analysis of net assets between funds (continued)

<b>As at 31 March 2020</b>	<b>Restricted Funds</b>	<b>Unrestricted Designated Funds</b>	<b>Unrestricted General Funds</b>	<b>Total</b>
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
Bank and cash	24,553	-	87,502	112,055
Other net assets	-	-	(42,724)	(42,724)
	<u>24,553</u>	<u>-</u>	<u>44,778</u>	<u>69,331</u>

## 20 Related party transactions

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

# ACKNOWLEDGEMENTS

Thank you to all the individuals and organisations who have supported our work during this difficult 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 our funders who have given grants, sponsorship or donations to support our work this year.

Akcea Therapeutics  
Albireo  
Alexion  
Amicus Therapeutics  
BioCryst  
Biogen  
Bluebird Bio  
Bond and Coyne  
Chiesi  
City Bridge Trust through London Community Response  
CORRA Foundation  
Covid-19 government emergency funding through National Lottery  
Gilead  
Illumina  
Incyte  
Janssen  
Kyowa Kirin  
Lupin Pharmaceuticals  
Medpace  
Novartis Gene Therapies  
Novartis Pharmaceuticals  
Orchard Therapeutics  
Pfizer  
PTC Therapeutics  
Rhythm  
Roche  
Sanofi  
Santhera  
Sarepta  
Sobi  
Spark Therapeutics  
Takeda  
The Catherine Cookson Foundation  
The Edward Gostling Foundation  
The National Lottery Wales  
UCB Celltech  
Vertex  
Vertex, Albireo  
Wellbeing Fund in Scotland  
Wellcome Trust

# OUR MEMBERS



The Aarskog Foundation



Action Duchenne



Action FCS



Action on Gilbert's Syndrome



Addison's Disease Self-Help Group



Adrenal Hyperplasia Network



Advocacy for Neuroacanthocytosis Patients



Albinism Fellowship UK Ireland



Alex, The Leukodystrophy Charity



ALK Positive Lung Cancer (UK)



Alkaptonuria Society



Alpha-1 Awareness UK



Alpha-1 UK Support Group



Alport UK



Alström Syndrome UK



Amy and Friends



ANE International



Angelman UK



Aniridia Network



Annabelle's Challenge



Anorchidism Support Group



Antenatal Results and Choices



Archangel MId Trust



Association For Glycogen Storage Diseases UK



Ataxia UK



Ataxia-Telangiectasia Society



Bardet-Biedl Syndrome UK



Barth Syndrome UK



Batten Disease Family Association



Beat SCAD



Beckwith-Wiedemann Support Group UK



Behçet's UK



BRCA Umbrella



British Heart Foundation



Cadasil Support UK



Cambridge Rare Disease Network



Cardiomyopathy UK



Cavernoma Alliance UK



CdLS Foundation UK and Ireland



CGD Society



CHAMP1 Patient Support Group



Charcot-Marie-Tooth UK



Childhood Eye Cancer Trust



Childhood Tumour Trust



Children's Liver Disease Foundation



Children's Mitochondrial Disease Network



Children's Health Scotland



CML Support Group



Congenital Adrenal Hyperplasia Support Group



Costello Support Group International



Cri Du Chat Syndrome Support Group



Cure and Action for Tay-Sachs Foundation



Cystic Fibrosis Trust



DC Action



DDDC3G Renal Support Group UK



Dercums Disease and Rare Disease Foundation UK



Diamond Blackfan Anaemia Support Group UK



Dravet Syndrome UK



Duchenne Family Support Group



East Lancashire Community Genetics Service



East London Branch Sickle Cell Society



Ehlers-Danlos Society



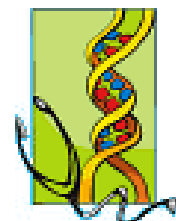
EHLERS-DANLOS SUPPORT UK



ELIJAH'S HOPE



FANCONI HOPE CHARITABLE TRUST



Fap Gene Support Group



Fibromuscular Dysplasia Society



Fibrous Dysplasia Support Society UK



Fight for Sight



Findacure



FND Hope UK



FSH Muscular Dystrophy Support Group



Fuchsfriends UK



Funny Lumps



GATA2 Deficiency Support Group



GENE People UK



George Pantziarka TP53 Trust



GIST Support UK



Gorlin Syndrome Group



HAE UK



Haemochromatosis UK



Haemophilia Society



Headlines Craniofacial Support



Hereditary Spastic Paraplegia Group



HPS Network UK



Huntington's Disease Association UK



Hypermobility Syndromes Association



Ichthyosis Support Group



IHH UK



Inherited Prion Disease Support Group



Jeune Syndrome Foundation



Jnetics



KIF1A.ORG



Kleefstra Syndrome



Krabbe UK



Leber's Hereditary Optic Neuropathy Society



Lipodystrophy UK



Local Families With Bleeding Disorders



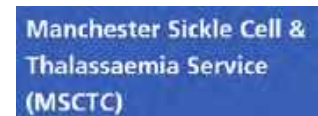
Lynch Syndrome UK



Macular Society



Making It Better - The Daniel Courtney Trust



Manchester Sickle Cell and Thalassaemia Centre



Marfan Trust



Mast Cell Action



Max Appeal



MEBO Research



Metabolic Support UK



Moebius Research Trust



Motor Neurone Disease Association



Mowat-Wilson Syndrome Support Group



MPGN/DDD Support Group



Muscle Help Foundation



Muscular Dystrophy UK



Myotubular Trust



Naitbabies



Narcolepsy UK



National Deaf Children's Society



NCBRS Worldwide Foundation



Nemaline Myopathy Support Group



Nerve Tumours UK



Niemann-Pick UK



NLRP12.COM



Noonan Syndrome Association



Ocumel UK



Osteopetrosis Support Trust



Pans PANDAS UK



Parathyroid UK



Pemphigus Vulgaris Network



Pitt Hopkins UK



PNH Support Group



Prader-Willi Syndrome Association UK



Primary Ciliary Dyskinesia Family Support Group



Primary Immunodeficiency UK



PSC Support Group



Pseudoxanthoma Elasticum Support Group



PTEN UK and Ireland Patient Group



Rare Autoinflammatory Conditions Community - UK



Rare Dementia Support



RETT UK



Reverse RETT



RING20 Research and Support UK



SADS UK



Salivary Gland Cancer UK



Scleroderma And Raynaud's UK



Sense Usher Service



Shwachman-Diamond Support UK



SOFT UK



Special Needs Jungle



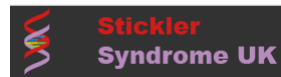
Spinal Muscular Atrophy UK



Spotlight YOPD



Stargardt's Connected



Stickler Syndrome UK



Stiff Person Syndrome



Thalidomide Society



The Aortic Dissection Charitable Trust



The Aplastic Anaemia Trust



The British Porphyria Association



The Children's Hyperinsulinism Charity



The Fragile X Society



The Gauchers Association



The Lily Foundation



The Maddi Foundation



The MPS Society



The Smith-Magenis Syndrome Foundation UK



The UK Mastocytosis Support Group



Thyroid UK



Timothy Syndrome Alliance



TreatSMA



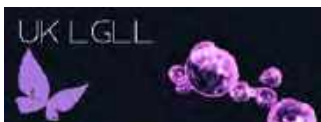
TRPS Support Group UK



Tuberous Sclerosis Association



Turner Syndrome Support Society UK



UK LGLL



UK Thalassaemia Society



UKPIPS



Unique - Understanding Chromosome Disorders



Urddad Foundation



Vasculitis UK



VHL UK/Ireland



Williams Syndrome Foundation Limited



Wilson's Disease Support Group UK



Wolfram Syndrome UK



Womb Cancer Support UK



Worster-Drought Syndrome Support Group



XLP Research Trust



XP Support Group



Yellow Brick Road Project Inc