2022/2023

IMPACT REPORT

A YEAR IN REVIEW

GENETIC ALLIANCE UK

Steve White, Vice Chair and Trustee, with his wife, Jo Milne, founder of CUREUsher, and children. After being diagnosed with Usher syndrome, Jo set up CUREUsher to fill the need for a dedicated charity for Usher syndrome in the UK.

Genetic Alliance UK invites and empowers us all to take our own agendas, our own considered concerns for those we represent to places that we might not have been able to reach on our own. One passionate voice, anchored in authenticity and patient centricity clearly, has meaning – many voices anchored by the same spirit has a power and an insistence that is unified, disruptive and made for change.

Steve White, Vice Chair and Trustee, CUREUsher

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The cover image shows Aurora who lives with an undiagnosed condition. The photo was taken at an Undiagnosed Children's Day event organised by SWAN UK - Cymru.

BACKGROUND

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.

Although 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 rare condition affects fewer than one in 2,000 people.

One in 17 people are affected by a rare disease at some point in their lifetime.

It is currently estimated that there are **over 7,000 rare conditions**, with new conditions regularly identified through scientific progress.

Eight out of 10 rare conditions are caused by a change to someone's genetic code.

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.

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**.

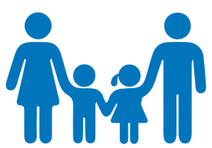
Each year **around 6,000 children in the UK** are born with a genetic condition so rare that it does not yet have a name.

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.

Rare and genetic conditions can be life-limiting and life-threatening.

Seven out of 10 rare conditions affect children.

More than **three 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.

MESSAGE FROM OUR CHAIR AND CHIEF EXECUTIVE

Genetic Alliance UK is an alliance of over 230 charities and support groups. The end of the membership and financial year 2022/23 is an opportunity for us to reflect on the past 12 months and acknowledge the progress we've made together.

Rare conditions are individually rare, but collectively common, affecting 3.5 million people in the UK. We hope that sharing what we've achieved together over the last year demonstrates that our voices are stronger when we collaborate and work together.

We're proud to amplify the diverse voices of organisations representing people living with genetic and rare conditions. We couldn't do what we do without our members, and our successes belong to you.

In addition to highlighting our shared achievements from the past year, please be assured that we're firmly focused on the future as we develop our plans for 2023/24 and a new strategy for 2024-29. We look forward to continuing to work with you and on your behalf in the years ahead.

Elizabeth Porterfield,
Chair, Genetic Alliance UK

Louise Fish,
Chief Executive Officer, Genetic Alliance UK

OUR PRIORITIES FOR 2022/23

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

Growing our alliance and supporting our members

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

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

Ensuring scientific breakthroughs in genomics drive better research and services

Promoting opportunities to expand screening in line with international best practice

Genetic Alliance UK runs 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.

Objectives and aims

Our five-year strategy from 2018-23 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 2018-23 strategy on our website.

During 2022/23 trustees and staff worked collaboratively with members and supporters to develop 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 21.

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 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 we provide with free membership (annual income under £10,000). Five out of 10 of our members are small charities with membership fees of £50 each year (annual income under £250,000).

New members in 2022/23

In 2022/2023 **16*** **organisations have become members of Genetic Alliance UK**

*triple the number who joined in 2020/21

Attendees at our Rare Disease Day reception at Westminster; attendees included representatives from our member organisations, people with lived experience, MPs and healthcare professionals.

Three out of 10 members are micro charities* who we provide with free membership

*(charities with an annual income under £10,000).

Five out of 10 members are small charities* with a £50 membership fee

*(charities with an annual income under £250,000).

During 2022/23 we hosted 21 weekly Community Check-ins with an average attendance of 20 members. From January 2023, Check-ins were replaced by our new Member Briefings and Member Brews, each held monthly via Zoom to improve accessibility for attendees.

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, increased promotion of awareness days and weeks, and improved engagement through social media channels and member communities.

Matthew Carr at Retina UK's Annual Conference.

At Retina UK, one of our core values is 'Collaborative'. This value sits hand in hand with the way in which Genetic Alliance UK works with its members. With regular newsletter briefings sharing information across the rare, genetic and undiagnosed conditions space, having the opportunity to showcase the work of our charity in a Member Brew or even taking over their social media feeds for a day, enables us to fulfil our collaborative value.

Matthew Carr, Strategic Lead – Campaigning, Influencing and Policy, Retina UK

Building Rare Resilience

Over the past year we've delivered 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. 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. Every workshop had over 50 attendees and received overwhelmingly positive feedback with almost 100% of participants confirming the workshops had been beneficial.

Bob Stevens, CEO of MPS Society (left) and Helen Whately, Minister of State for Health and Social Care, attending our Rare Disease Day 2023 parliamentary event for England.

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.

Jennifer Jones, Genetic Alliance UK's Research Associate, presenting our work on newborn screening with our member organisation, Alex TLC, at their Community Weekend.

Our research team have been involved with:

5 active research projects:
- SWAN couples counselling – a qualitative interview project exploring the experience of therapy for couples and therapists
- Rapid Genomic Sequencing – a large scale project evaluating rGS
- Quant survey data – further statistical analysis of our 2020 Rare Experience Survey
- Alex TLC – research on 'Attitudes towards newborn screening'
- Report on equity of access to advanced therapies in the UK – on behalf of ATMP Engage

4 Scientific papers/visual engagement pieces published where Genetic Alliance UK staff were a lead or co-author

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. It sets out the commitment of UK governments to improve the lives of people with rare conditions over the next five years. Our 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.

Blessing speaking at our Westminster parliamentary event for Rare Disease Day, sharing her experiences of living with a rare condition.

Maximising opportunities to raise awareness on Rare Disease Day 2023

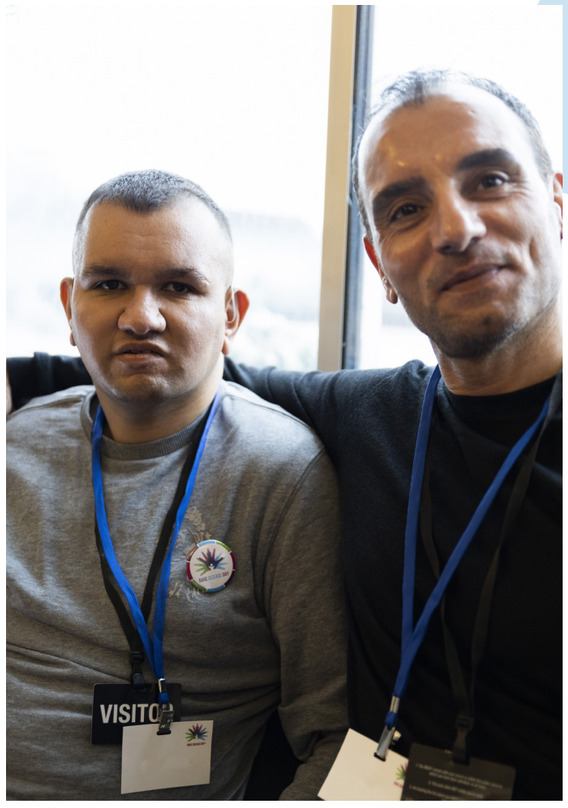
On Rare Disease Day on 28 February, we worked hard with our members to raise awareness of the challenges facing people living with rare conditions and their families. In 2023 we used the high profile of this annual awareness day to focus on one of the key challenges identified by people living with rare 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 on our website.

only **one** out of **10**

adults have a care plan

A focus of Rare Disease Day 2023 was the launch of our new policy report, *Coordinating care: learning from the experiences of people living with rare conditions*. Our members contributed case studies of good practice such as the Alström Syndrome Centres of Excellence and the NHS Tuberous Sclerosis Clinics Network across the UK. We highlighted the need for better coordination through an article in the Guardian Rare Disease Day supplement, and produced a short film highlighting a member case study on good care coordination with support from ITN Business. We rounded off a busy day by bringing together our members with parliamentarians and senior decision makers from the NHS and civil service at a Westminster reception focused on care coordination. We hosted a similar in-person reception in Wales, as well as an online Scotland reception and virtual joint nation event to engage as many people as possible.



Kez (right) and his son Hassan, who lives with Alström syndrome. Kez shared their case study for our Rare Disease Day report on care coordination.

Kerry Leeson-Beevers, Chief Executive at Alström Syndrome UK, said:

'Alström syndrome is an extremely rare and complex condition and we are lucky to have two centres of excellence in Birmingham. We value the partnership that we have with clinicians as this enables us to provide holistic care and support to those affected by the condition in the UK. We know how fortunate we are to have this service, and more work needs to be done so that all people affected by rare conditions have access to equitable care and support.'

Dr Pooja Takhar and Luke Langlands, Joint Chief Executives at the Tuberous Sclerosis Association, said:

'The NHS TSC Clinics Network demonstrates the massive impact that coordinated care can have on diagnosis, care and management of a rare condition. Where there were once individual clinics producing important but siloed care, we now have a network of specialists encouraging equitable care across all UK nations.'

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 were 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.

3 **Using NHS Scotland**

2 **Y daith at ddiagnosis**
2 **The journey to diagnosis**

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.

Rhys, who lives with superficial siderosis attending the Welsh Rare Disease Day event with his mum.

During 2022/23 we also:

- Published our 2018 research on the importance of mental health care for people living with rare conditions in a scientific journal.
- Worked with the Welsh Registry for Rare Diseases (CARIS) to support development of their self-registration service for adults with rare diseases.
- Undertook work in collaboration with support organisations and healthcare professionals in Scotland to improve awareness of rare conditions in NHS Scotland.
- Jointly delivered a workshop and report on communication for advanced therapies which included individuals affected by rare conditions, with the resulting report hosted on the EuroGCT website.

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 our members' views on rare conditions, diagnosis, 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 voices

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 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 assist MSPs and their caseworkers in supporting 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 recognises other genetic conditions with overlapping needs to Down's Syndrome, facilitating engagement with other charities and the Department of Health and Social Care. We ensured the voices of people living with other genetic conditions were considered in the implementation of the Act.

Activities in brief

In 2022/23 we responded to a variety of consultations from the governments across the UK, healthcare and fertility regulators, healthcare delivery partners and other bodies, including:

21 National Institute of Health and Care Excellence (NICE) scoping consultations responded to.

37 preimplantation genetic testing license requests had patient perspective statements submitted as evidence to the Human Fertilisation and Embryology Authority (HFEA).

31 further consultations responded to by the UK, Scottish and Welsh governments, NHS and wider decision makers on a variety of topics.

4. ENSURE 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.

Our SWAN UK Parent Reps who attended a weekend away.

SWAN UK – Cymru

SWAN UK Cymru has established a Sounding Board, consisting of six SWAN UK members in Wales.

The first face-to-face networking family event for members in Wales took place in Spring 2022 with 12 adults and 14 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.

SWAN UK - Cymru Dad:

'It was extremely valuable to spend time with like-minded dads whose lives have been turned upside down by our life circumstances. The afternoon was brilliant and it really helped with my mental health. We are all very appreciative of the support and the activity was brilliant.'

Claire Swan, our SWAN UK parent representative for South Wales, continues to be very active in providing support to families in the local area. Claire continues to build on the relationship she has made with her local Sainsbury's store and as a result they continue to donate goods that Claire distributes to SWAN UK families in South Wales.

A young boy whose family is a member of SWAN UK playing with a Disney princess at an Undiagnosed Children's Day event in Wales.

SWAN UK parent:

I genuinely cannot thank you enough for this food donation. It's come at the most perfect time. We've had a difficult few months with my husband being off work and he's only just gone back this week. This will help us SO much. Honestly, I could cry. You guys are amazing.

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 13 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.

We have

3825

SWAN UK members

153 new SWAN UK members in 2022/23

114 attendees at **8**

face-to-face SWAN UK networking events and trips held in 2022/23

Citizens' Jury on Genome Editing of Human Embryos

We recruited 21 individuals from our community 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 with 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.

Activities in brief

Working in partnership with the Wales Gene Park, we continue to engage patients, families, patient organisations and the public in genomics in Wales, including:

Establishing six-weekly Genomics Cafés across Wales for members of the public to find out about new advances in genomic medicine, reaching an audience of around 60-200 attendees including Genetic Alliance UK members.

Engaging young people through quarterly Young People's Genomics Cafés.

Working with Genomics Partnership to set up the Genomics Sounding Board, made up of 30 people with diverse experiences of rare genetic conditions and cancer testing or diagnosis.

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 population screening programmes. We have raised awareness of this issue throughout the year when speaking to journalists, clinicians, NHS managers and civil servants. For example, the newborn bloodspot 'heel prick' 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.

Bringing the challenge to life 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 to raise awareness of newborn screening for SMA won a bronze 2023 Lens Award and was shortlisted at the 2023 Smiley Charity Film Awards.

A shot of Portia and her son taken from our short film with ITN business for Rare Disease Day 2023.

Portia Thorman, SMA UK advocacy lead and mother of Ezra who lives with SMA, said:

"It's absolutely crazy that we don't have newborn screening in the UK. If we can find kids like Ezra when they're just born, and get this new drug into them then our lives would be completely different. I think about it a lot, and it just feels completely unfair."

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 Genomes 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 from the newborn bloodspot 'heel prick' screening programme to this development process.

Maxwell has SMA type 2. He wrote a blog about his life and experiences in August 2022 for SMA Awareness Month.

Activities in brief

We work collaboratively to raise awareness of the potential to expand current newborn and population screening programmes in the UK, including:

- Playing an active role in the Newborn Screening Collaborative chaired by the MPS Society.
- Sitting on the Blood Spot Task Group of the UK National Screening Committee to improve the evidence base to help the committee make rapid and robust decisions on newborn screening.
- Working with EURORDIS – Rare Diseases Europe and their working group on newborn screening.
- Being members of the Patient Advisory Group at Screen4Care, a European Project examining newborn screening using genome sequencing and using AI tools to examine health records and identify rare conditions.

THE YEAR AHEAD

2023/24 BUSINESS PLAN

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 People and Policies sub-committee alongside the existing Finance and Governance sub-committee.

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.

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 here.

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.

Genetic Alliance UK's senior staff. Nick Meade, Mary Edwards, Dr Amy Hunter, and Louise Fish at the Rare Disease Day parliamentary event in London.

Our objectives
(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.**

A SWAN UK member family at the Undiagnosed Children's Day event in Wales with A&S Animal Encounters.

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)

- 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.

Members attending our parliamentary reception on Rare Disease Day talking with our Senior Policy Officer, Rachel Clayton.

Our values
(the things we believe are important)

People-centred • **Collaborative**

Independent • **Influential** • **Inclusive**

Knowledge-generating • **Evidence-led**

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

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

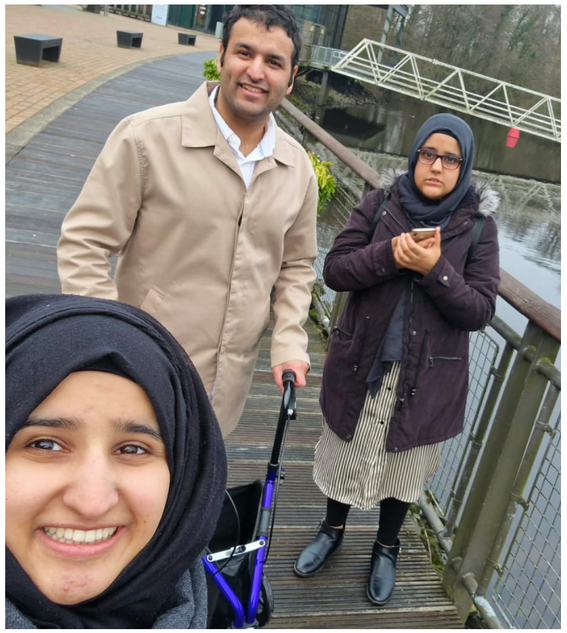
Genetic Alliance UK receives support from industry partners for projects that help us to deliver our charitable objectives. During 2022/23 we updated our policy on working with industry to set out clear principles and guidance for how we work with the life-sciences industry.

FINANCIAL OVERVIEW

The Impact Report contains the Statement of Financial Activities and Balance Sheet which form part of the charity's Annual Report and Accounts 2022/23.

Members can obtain full copies of the Annual Report and Accounts 2022/23 by emailing the Chair at chair@geneticalliance.org.uk. They are also available on the Genetic Alliance UK website, Companies House and from the Charity Commission.

Karen lives with pregnancy-associated osteoporosis and has written numerous blogs for Rare Disease UK.



Haider and family. Haider lives with a rare form of Cerebellar Ataxia, Autosomal Recessive Cerebellar Ataxia Type 1. Haider was involved in our Rare Disease Day 2023 campaign, writing a blog to share his experiences of living with a rare condition.

Statement of financial activities
Year ended 31 March 2023

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

Balance Sheet
As at 31 March 2023

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

Reference and administrative details

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 office: Genetic Alliance UK
Creative Works
7 Blackhorse Lane
London
E17 6DS

Email: contactus@geneticalliance.org.uk
Website: geneticalliance.org.uk
Facebook: GeneticAllianceUK
Twitter: @GeneticAll_UK
LinkedIn: Genetic Alliance UK

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

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

GENETIC ALLIANCE UK