GENETIC ALLIANCE UK STRATEGY

Driving progress: genetic, rare and undiagnosed

2018-2023

GENETIC ALLIANCE UK

ABOUT US

Our 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.

Our vision

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 values

We are honest, independent, creative, collaborative, evidence led and empowering.

Genetic Alliance UK

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

WELCOME

Genetic Alliance UK has championed the rights of those affected by genetic conditions for almost 30 years. In the year of our registration as a charity, the first comprehensive human genetic map had just been published and the human genome project was yet to come. The intervening three decades have seen an explosion of knowledge and we now stand on the brink of a new era of genomic medicine with growing potential to diagnose and develop effective and even curative treatments.

In November 2013, we welcomed the UK Strategy for Rare Diseases, which set out 51 commitments designed to improve health and social care for rare disease patients. In the intervening five years we have seen some progress, particularly in terms of genomic medicine. However, we have not seen a level of change sufficient to address fundamental problems, such as the diagnostic odyssey many patients endure and lack of equity of access to specialised care and innovative treatments. In the coming year, the UK will leave the European Union and we do not yet know what impact Brexit will ultimately have in terms of rare disease clinical research, access to new medicines and the ability of UK clinical experts to collaborate with European partners.

We know too that many of our member charities, and the people that they support, are facing tough times financially. It is vital that Genetic Alliance UK continues to support the work of the organisations in our alliance and this is why we are committed to reviewing our membership fee structure within the next five years. It is also critical that we keep front and centre the lived experiences of patients and families.

Our new strategy 'Building Better Futures' sets out our commitments to remaining relevant, innovative and creative. Our strategy focuses on the ways in which we will respond to the evolving research, clinical practice and policy environments. Key to delivering impact for our community will be keeping our promise to unite and amplify the voice of our collective communities.

In this document, we present our strategic objectives, articulate what success will look like and how we will work to achieve this and explain how we will measure our progress and impact. The Board of Trustees will receive and review progress reports on a quarterly basis and we will report back against our strategic aims in our annual reports. We will undertake a mid-term review of the strategy (beginning in 2021) so that the Board can take a view as to the need to refresh the strategy in light of progress and changes in the environment in which we operate and from feedback we receive.

We thank all those who completed our membership survey and/or have provided other feedback to Genetic Alliance UK. Your input has been invaluable and we look forward to working with you to build better futures for people affected by genetic, rare and undiagnosed conditions.

Jayne Spink
Chief Executive

STRATEGIC OBJECTIVES

DRIVING PROGRESS:

'Improving outcomes for everyone affected by genetic, rare and undiagnosed conditions through evidence-based influencing and campaigning.'

Building our community:

'Supporting and developing communities by providing an excellent range of services to our members, new groups and everyone affected by these conditions.'

Building greater awareness:

'Creating the impetus for positive action by increasing understanding within the general public, the health and social care community, and with policy makers.'

Building our organisation:

'Maximising our capacity to deliver a programme of sustainable growth, continued improvement and development.'


Building our community
DRIVING PROGRESS
Building greater awareness
Building our organisation

DRIVING PROGRESS

Improving outcomes for everyone affected by genetic, rare and undiagnosed conditions through evidence-based influencing and campaigning.

We believe that everyone living with a genetic, rare or undiagnosed condition should be able to receive high quality services, treatment and support. Genetic Alliance UK provides support and participation opportunities, keeping the needs and preferences of our community at the heart of the debate and central to policy and service development. The evidence we generate through our research activities ensures we are able to speak with authority when we campaign.

Rare Disease UK is the national campaign run by Genetic Alliance UK, providing a united voice for the rare disease community. We work with our supporters to raise the profile of rare diseases and seek to bring about lasting change offering better health and quality of life for individuals and families. We work with health departments across the UK to implement the UK Strategy for Rare Diseases to ensure that those living with rare conditions have equitable access to timely and accurate diagnosis, high quality services, treatment and support.

Genetic Alliance UK was one of very few patient organisations to campaign to stay in the European Union. Our basis for this choice was that cross-border collaboration, research funding networks and regulatory harmonisation are crucial to the rate of progression towards addressing the unmet health need that people living with a genetic, rare or undiagnosed condition face. As the UK exits the European Union, we need to work to ensure the collaboration, networking and harmonisation is preserved or improved as much as possible.

To achieve positive change for all those affected by genetic, rare and undiagnosed conditions we will:

1. Continue to lobby for a refresh and renewal of the UK Strategy for Rare Diseases so that this can be in place before the current strategy expires (2020).

2. Work collaboratively and creatively with statutory organisations, regulatory bodies and commissioners and providers of services.

3. Continue to develop our strong political networks across the UK, highlighting the measures that should be taken to improve the lives of people affected by genetic, rare and undiagnosed conditions.

4. Continue to produce robust, accurate, timely and targeted briefings to support parliamentary activity.

5. Continue to support the work of the Westminster All Party Parliamentary Group and Cross Party Groups in Wales and Scotland on Rare, Genetic and Undiagnosed Conditions, through provision of the secretariats.

6. Act as a focal point of communication on policy issues for everyone affected by genetic, rare and undiagnosed conditions and the organisations and professionals who support them.

7. Ensure our members have a say in the policy work that we do, by delivering tailored consultative opportunities ranging from long-standing consultative panels, day-long workshops, remote webinars, questionnaires, and informal consultation.

8. Identify key topics for our members and community, on which to undertake proactive and unified activities, deliver a targeted and unified message to policy makers.

9. Identify gaps in the evidence base and fill them, continuing to generate robust evidence through our own research projects and through review and analysis of quality research published by others.

10. Develop stronger links with researchers and research funders, promoting interest and investment in rare disease research.

11. Work collaboratively and creatively with other stakeholders across public, private and the third sector for the benefit of our community.

12. Build, maintain and prioritise collaboration with European partners and participation in international initiatives. Continue to work to ensure we fulfil our role as the UK National Alliance member of Eurordis.

What will success look like?

Acting on robust evidence, we will have achieved positive changes for people living with genetic, rare and undiagnosed conditions. The UK Strategy for Rare Diseases will have been reviewed and refreshed taking us beyond 2020, with clear commitments and a clear mechanism for coordinated implementation across the four nations.

The rare, genetic and undiagnosed community will continue to have a productive relationship with partners based within the European Union.

Stakeholders working on improving the environment for access to rare disease medicines will be able to refer to a clear vision for a transparent, equitable and rational method for decision making.

The voice of the genetic, rare and undiagnosed patient community will have been heard and responded to in the transition from large scale genome sequencing research projects (such as Deciphering Developmental Disorders and the 100,000 Genomes Project) into mainstream care.

How will we measure impact?

We will evaluate the success of our activities by:

- Evaluating the impact of our proactive policy projects, monitoring whether and by whom our recommendations have been taken up.
- Measure our levels of parliamentary engagement and map our networks of influence.
- Map and measure patient and public involvement roles that we support, promote and secure.
- Count the number and evaluate the range and impacts of our consultative activities.
- Monitor the number of policy consultation sessions delivered by our Policy Team and seek feedback from our member groups on their impact.
- Map our evidence base, evaluating the volume, range and quality of our research and the contributions and impacts of research on our policy work.

BUILDING THE COMMUNITY

Supporting and developing the genetic, rare and undiagnosed communities by providing an excellent range of services to our members, new groups and everyone affected by these conditions.

Providing an excellent service to a growing membership

Supporting patient organisations is the key to delivering positive change for people affected by genetic, rare and undiagnosed conditions. We have learned from our membership survey that the strength gained from being part of our wider community is the main reason organisations choose to join Genetic Alliance UK.

There are around 8,000 known rare conditions. Research has shown that the majority of rare conditions have an underlying genetic cause or component (current estimates are around 80%). The cause of the remainder is a subject of research, and, in some cases, clear genetic links are being identified. Almost all single gene disorders are rare. 99% of our members support people with rare conditions, support research into rare conditions, or both. This close relationship between rare and genetic conditions is reflected at the level of policy development. It makes sense that we ensure our work is inclusive of all concerned with genetic, rare and undiagnosed conditions.

To provide an excellent service to our growing membership we will:

1. Ensure that we continue to be guided by the priorities and choices of our membership by seeking and taking into account their feedback, ensuring our trustee board reflects membership and working closely with people affected by genetic, rare and undiagnosed conditions.

2. Introduce new categories of membership that will help us to build closer working relationships with researchers and healthcare professionals.

3. Convert eligible voluntary sector supporters of Rare Disease UK to membership of Genetic Alliance UK.

4. Further develop our programme of member benefits, offering more flexible up-skilling, networking and participation opportunities across the UK, empowering our community through training and expert support to better deliver against their aims.

5. We will review our membership fee structure during the first year of the strategy, with a view to removing any barriers we identify so that more organisations are able to access our benefits.

6. Improve the targeting of our communications to members through our newsletters, interactive workshops, webinars and the development of member–only online resources.

7. Extend our 'Building Rare Communities' programme of support and training for new and fledgling groups.

What will success look like?

By 2023 we will have increased the number of Genetic Alliance UK members by at least 20 per cent (with a target of 240) and in doing so we will have increased our ability to invest in developing and delivering our member services. This growth in membership will in part be linked to our success in supporting the development of new member organisations through our Building Rare Communities programme.

More of our members will tell us that the opportunities, information and resources we have delivered have had a positive impact on their ability to deliver against their own individual aims and objectives.

The number of members participating in our events and accessing member services will have increased in all four nations, and we will see uplift in our already extremely high level of member satisfaction.

How will we measure progress and impact?

In 2017 we carried out an 'audit' of our membership in order to better understand how it was made up. We also ran our first comprehensive member survey in order to guide the development of our strategy. We have also solicited feedback on our events and services on an ongoing basis. Together these three data sets form our pre-strategy baseline.

We will evaluate the success of our activities by

- An annual membership audit.
- A biennial membership satisfaction and involvement survey.
- Gathering feedback in relation to individual events and services on an ongoing basis.

Providing an excellent service to the undiagnosed community

Part of Genetic Alliance UK, the SWAN UK (syndromes without a name) network enables us to fulfil our commitment to support all those affected by genetic conditions, regardless of whether or not they have yet received a diagnosis. Through SWAN UK, undiagnosed families have access to support and information as well as the opportunity to guide and contribute to the work of Genetic Alliance UK. The undiagnosed community are on the frontier of the development of genomic technology, some of the first to feel the benefit of whole genome sequencing. By working so closely with them, we gain insights and knowledge that we can share to benefit everyone affected by genetic conditions.

Approximately 6,000 children are born in the UK each year with a genetic condition so rare their diagnosis may take several years, if they ever receive one. Currently 50% of children and young people having genetic testing through NHS clinics will not get a confirmed diagnosis for their condition. Over 80% of SWAN UK member families are currently taking part in genome sequencing which currently has a successful diagnostic rate of between 25-40%.

SWAN UK is the only source of support and information available in the UK to the families of these children and young people. At the time of writing, over 1,700 families are registered to receive support and information.

These families are at the very start of their diagnostic odyssey. When and if they receive a diagnosis, it is highly likely they will then go on to join a relevant member charity of Genetic Alliance UK to access support and information. Where no specific charity exists, families may chose to join forces with others in order to bring one into being, supported by our Building Rare Communities project.

To provide an excellent service to the undiagnosed community we will:

1. Establish a SWAN UK Parent Council that will act as a consultative panel as we implement and review progress of our strategy. The Chair of the SWAN UK Parent Council will have Observer status on the Board of Trustees.
2. Continue to ensure that members of the SWAN UK community are able to take up opportunities for participation in the wider work of Genetic Alliance UK.
3. Further develop online and remote support for SWAN UK families at a national level, whilst seeking resources to improve equity of access to local support across the UK.

What will success look like?

By 2023 we will have increased our reach (meeting our target of over 2,000 families supported), providing greater equity of access to all families, and family members, including those who live in hard to reach communities. More families will have access to information that will help them access the support and care that meets their individual needs and preferences, regardless of where they live in the UK.

Our SWAN UK Parent Council will have contributed to the delivery of our strategy by actively engaging with the wider policy, research and public engagement work of Genetic Alliance UK and acting as ambassadors to promote, develop and support the undiagnosed community.

SWAN UK Local Networks will be running across the UK with sustainable funding, so that SWAN UK members can have confidence that they will have access to ongoing support, whenever and for as long as they need it.

How will we measure impact?

We will evaluate the success of our activities by:

- An annual membership audit.
- A membership satisfaction survey every two years.
- Measuring the number of Local Networks and the numbers of families engaging with our events and activities across the UK.
- Measuring our levels of engagement with healthcare and other relevant professionals.
- Measuring the numbers of publications requested and downloaded.
- Measuring open rates on SWAN UK newsletters, social media reach and levels of engagement with SWAN UK social media channels.

BUILDING GREATER AWARENESS

Creating the impetus for positive action by increasing understanding of genetic, rare and undiagnosed conditions, within the general public, the health and social care community, and with policy makers.

Raising the profile of genetic, rare and undiagnosed conditions is vitally important because it:

- is critical to forming connections and building communities of support,
- helps ensure people are diagnosed correctly and as soon as possible,
- drives research and helps promote uptake of innovations in treatment and care,
- builds the platform from which we deliver our influencing and campaign working.

In addition to maximising the impact of the awareness days on which we lead in the UK (Rare Disease Day and Undiagnosed Children's Day), increasing the reach of our day to day communications and promoting our outputs and messages is key. Our ambition is to provide a focal point for the genetic, rare and undiagnosed community. We aim to take the public, opinion leaders, policy makers and professionals on a journey that begins with increased awareness and carries forward into positive action.

To increase understanding of genetic, rare and undiagnosed conditions we will:

1. Increase our press and media activity and the audience and reach of our online media channels through creative and engaging content and experimenting with new channels as they become available.

2. Develop our new website with new functionality and vibrant, quality content.

3. Support our members to increase their own reach, supporting their communications and through the sharing of skills and media opportunities.

4. Develop a growing programme of public engagement activities, delivered in collaboration with organisers of community events, schools, learned societies, professional bodies and academic/ public institutions.

5. Conduct an annual horizon scan of new and emerging technologies, delivering research and activities designed to enable patients and the public to better engage with developments in research, policy and clinical care.

6. Develop stronger links with researchers, funders of research and healthcare professionals, creating tailored products to engage, collaborate and educate.

What will success look like?

We will see more coverage of our activities and of genetic, rare and undiagnosed conditions across all external communications, using both social media and traditional channels. The British public will become more aware of the relevance of genetic, rare and undiagnosed conditions to their own family and social circles. More people will engage with the issues and be motivated to take action (sharing content, donating, fundraising). Our reach will have increased by at least 25% across all platforms.

Our programme of public engagement activities will have grown such that we have reached 10,000 new people and by our mid-term will be generating sufficient funds to cover its costs and generating surplus to help support our core activities by the end of our strategic period.

We will have encouraged professionals to take a greater interest in developing their own knowledge of genetic, rare and undiagnosed conditions and to incorporate that knowledge into their practice - thereby improving patient care.

How will we measure impact?

We will evaluate the success of our activities by:

- Our reach (numbers and range of different stakeholders signed up to mailing lists), and crucially engagement (click throughs/ action) in e-communications.
- Uptake of our press releases by press and media.
- Our website traffic and number of unique users / hits.
- Reach of our national awareness days; in terms of media coverage, social media reach and the number of institutions and businesses engaging with them.
- Levels of activity, engagement and satisfaction for our public engagement programme.
- Return on investment of our public engagement programme.

BUILDING OUR ORGANISATION

Maximising our capacity to deliver a programme of sustainable growth, continued improvement and development.

Growing our income

Genetic Alliance UK charges membership fees proportionate to income for charities whose income exceeds £10,000 per annum. These fees represent less than 5% of our total income. We are committed to ensuring value for money for our paying members and to ensuring that any future increase in our membership fee structure is kept well within the rate of inflation. This means that growing our fundraised income and developing new income streams will be of growing importance in the years ahead. As we progressively grow our income, we will work to a balanced budget, raising as much money as we spend each year.

To deliver on our fundraising aspirations we will:

1. Pilot new fundraising activities and re-energise campaigns or relationships that have fallen dormant and develop those which provide a good return on investment.
2. Build and support our community of active fundraisers with creativity, tailored support and resources. Our calendar of activities will have something for every age and ability so there will be no barriers to fundraising for us.
3. Seek new donors and supporters and by improving stewardship encourage long-term giving relationships.
4. Explore new opportunities for income generation, expanding corporate sponsorship and attracting major donors by capitalising on our national awareness days.
5. Create a flagship fundraising event, with a guaranteed income each year.

What will success look like?

By the end of our five-year strategy we will have met our targets to increase income and have become the charity of choice for a number of key donors. Our income will have increased year-on-year and we will be less reliant on any individual income source or stream because our portfolio of income will be more diverse. We will have developed a network of fundraisers and donors whose loyalty will be driven by our commitment to our values and our demonstrable and significant impacts.

Our ethos of continuous improvement will ensure that our systems and processes are fit for purpose and that we are using the most efficient tools and resources available in delivering our work.

What will we measure?

We will evaluate the success of our activities by:

- Our overall expenditure and income.
- Our overall diversity of income and return on investment for each stream, comparing these to industry averages (as published by the Institute of Fundraising).

Valuing and developing our expertise

One of Genetic Alliance UK's major strengths is the skill, experience and knowledge of its team. We have strong expertise in communications, fundraising, research, engagement, public affairs and policy which allows us to deliver the high-quality work that we are known for. We have bases in London, Edinburgh and Cardiff, the latter as part of an agreement with the Wales Gene Park.

We will practice an ethos of continuing improvement so our staff and volunteers will feel valued and supported in their own development. We will work to empower, improve and retain our team. We will examine our ability to deliver this strategy from the staffing and locations that we currently have, and will adjust these to ensure efficiency and impact as necessary according to the needs of our team and our resource.

To promote an environment conducive to continuing improvement we will:

1. Continue to implement our performance and development review process with existing staff, to identify training needs and progressive changes to the remits and responsibilities of our team.

2. Examine our impact within the four nations of the UK, and the needs of the populations our offices serve. This will allow us to build a plan to ensure we are truly a UK-wide organisation.

3. Continue to collect information within the organisation that can preserve the organisational memory of Genetic Alliance UK.

What will success look like?

Our staff team will be highly productive, effective, motivated and collaborative. New team-members will be empowered to quickly join and feel part of the team. Existing team-members will be

empowered to learn, take on more responsibility and grow within the organisation. Our impact in the four nations of the UK will be more proportionately uniform.

What will we measure?

We will monitor achievement and quality of support, supervision and training for all our staff through our annual performance and development reviews.

Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 200 patient organisations.

Our aim is to ensure that high-quality services, information and support are provided to all who need them. We actively support research innovation across the field of genetic medicine.
geneticalliance.org.uk

Rare Disease UK is the national campaign for people with rare diseases and all who support them. The campaign works with health departments across the UK to implement the UK Strategy for Rare Diseases to ensure that patients and families living with rare conditions have equitable access to high quality services, treatment and support.

Rare Disease UK is run by Genetic Alliance UK.
raredisease.org.uk

SWAN UK (syndromes without a name) is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. SWAN UK's Big Ambition is that all families who have a child affected by a syndrome without a name get the support they need, when they need it.

SWAN UK is run by Genetic Alliance UK.
undiagnosed.org.uk