GENETIC ALLIANCE UK
Membership offer 2022-2023
ABOUT GENETIC ALLIANCE UK

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 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 is a multi – stakeholder campaign run by Genetic Alliance UK, working with the rare disease community and the UK's health departments to effectively implement the UK Strategy for Rare Diseases. Rare Disease UK is the official organiser of Rare Disease Day in the UK.

SWAN UK is a support network for families of children and young adults affected by a syndrome without a name - a genetic condition so rare it is often impossible to diagnose.

We have an experienced and long standing staff team with backgrounds in natural and social sciences and are governed by a Board of Trustees made up of representatives from our member organisations.

If you want to know more, read our five year strategy.

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Website: geneticalliance.org.uk
Facebook: GeneticAllianceUK
Twitter: @GeneticAll_UK
Instagram: geneticallianceuk

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

Use of Genetic Alliance UK logo

Organisations applying to become members of Genetic Alliance UK go through a due diligence check, where we ask for information relating to governance and charitable activities. Our members tell us that being a member of Genetic Alliance UK and having our logo on their website serves as a kitemark of quality for funders and other relevant stakeholders.
WHO CAN JOIN?

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, rare and undiagnosed conditions and campaign for the broad issues which affect all of our members.

You don’t need to be a registered charity to join, but we do ask that you have a governing document and a minimum of two unrelated people involved in running your group.

WHY JOIN GENETIC ALLIANCE UK?

By being a member of Genetic Alliance UK, you are joining a strong, united voice and will ensure the needs of you and those you represent are heard at the heart of government and numerous other policy making bodies across the UK.

Our close working relationships with Parliamentarians in the nations of the UK, and the Departments of Health, the four NHSs, and all of the other arms length bodies, like National Institute for Health and Care Excellence (NICE), UK National Screening Committee and others make this possible.

We also provide the secretariat for the All Party Parliamentary Group (APPPG) and Cross Party Groups (CPG) in Wales and Scotland on Rare, Genetic and Undiagnosed Conditions.

Our team are experts in health policy, in bringing together individuals and organisations around key issues, and we conduct socio-economic research into the lived experience of individuals and carers affected by genetic, rare and undiagnosed conditions. One of our latest projects, the ‘Good Diagnosis Report’, investigated what a good diagnosis journey looks like for people with rare conditions, and the report was informed by several workshops we ran with individuals from our member organisations.

Whether you are a small organisation run by one person, or a much larger organisation run by many, we can aid you in your objectives to better advocate and support those you represent. The broad spectrum of our work means we can tailor our membership offer to suit your needs.

As a member you will have voting rights at our AGM and be able to nominate trustees to sit on our Board so your organisation can play a direct role in the governance and strategic direction of Genetic Alliance UK.

To talk to us about the benefits of membership for your organisation or have any questions email membership@geneticalliance.org.uk.

‘Genetic Alliance UK represents the needs of all those in the UK affected by rare conditions in the ‘corridors of power’ and allows those small groups to access this level of government.’

Genetic Alliance UK member
INCREASE THE REACH OF YOUR ORGANISATION

By being a member of Genetic Alliance UK, your organisation can reach more people, including researchers, health care professionals, media, funders and individuals in the genetic, rare and undiagnosed community.

AMPLIFY YOUR VOICE VIA OUR:

15k followers on Twitter
4k newsletter subscribers
35k website page views a month

Access to our Communications Team

Our communications team are dedicated and have previously been highly commended and nominated for awards for their work, including in The Third Sector Awards, as well as the Charity Film Awards. Our team has experience of tailoring and delivering engaging and dynamic content to a range of audiences and are always keen to collaborate.

Promote your activities in our newsletters

As a member, you are also invited to use our newsletters and website to promote the work your organisation does and to share news of your achievements. Our Genetic and Rare News mailing list includes 4,000 individuals.

Opportunity to write blog posts for our website

Our website achieves on average 35,000 page views per month and this is growing, which makes it an invaluable way to share your news, activities and case studies. Sessions on the Genetic Alliance UK website increase significantly in February around Rare Disease Day so it’s a great opportunity to get your community involved in sharing their stories or key information about your work.

Raise your profile in the press

We have links with many major news media outlets and we are often contacted by journalists interested in the field of genetics and rare conditions; we always strive to place our members’ stories and voices at the forefront.

Social media takeovers

As a member you will be encouraged to access our social media channels to raise awareness of your work, promote events and awareness days and reach new stakeholders and audiences. We have active social media channels, which include 15,000 followers on Twitter and a growing LinkedIn presence.

‘We thought the takeover was incredibly successful. We gained more followers, especially from the UK and received comments including “I’ve not heard of this disease before”. Definitely interested in taking over again.’

SynGAP Research Fund (SRF)
INCREASE THE IMPACT OF YOUR ORGANISATION

By being a member of Genetic Alliance UK, your organisation can increase its impact through access to consultations and engagement opportunities for those you support and consultation sessions with our Policy team.

‘I want to thank Nick and Farhana for the support for my participation in the APPG. It was really empowering and I’m now speaking more often on the issue and feeling more confident with speaking in public.’

A member who spoke at a meeting of the APPG on Rare, Genetic and Undiagnosed Conditions

Weekly parliamentary updates

As a member you will have access to our weekly monitoring of parliamentary content. This tool keeps you up to date on parliamentary activity that affects your community.

Access to patient engagement opportunities

We advocate for our members to have a voice in policy development and research, we then share these opportunities with our networks.

Access to our Policy Team

Our Policy and Public Affairs teams have a wealth of expertise including campaigning and advocacy, access to genetic tests and other diagnostics, UK rare disease policy, rare diseases in the EU, organisation of specialised healthcare in the NHS and access to medicines, research regulation and funding, clinical trials, support with NICE technology appraisals genetics and insurance and more. Our Policy and Engagement Managers in Scotland and Wales are also available to provide support regarding policy in the devolved nations.

Speaking at your conferences

Genetic Alliance UK staff have knowledge and expertise on a range of topics, including policy, public affairs, research, communications, fundraising and public engagement and would be delighted to support your community by attending or speaking at your conferences, subject to availability.

‘When we realised that we had neither the staff capacity nor expertise to conduct and analyse a survey on the mental wellbeing of our members, we found the perfect solution in contracting the work to Genetic Alliance UK. Their approach was collaborative and helpful and an excellent report was produced’.
By joining Genetic Alliance UK, you will situate your organisation within a much larger rare disease network, from which you can contribute, learn and make many meaningful connections. Together, as a strong, united voice we can better ensure the needs of the rare community are being heard and listened to.

Link with other groups
Whether you want to team up with other organisations working in similar areas to you, facing similar challenges or supporting people affected by similar symptoms, we can help you identify them, introduce you and support you to work together.

Join our members’ only Facebook group
As a member of our growing Facebook group you can network with other members, share your events and information and ask questions to get tips and ideas from each other.

Weekly Community Check-in
Every week we host a virtual Community Check-in with all our members, which we regularly invite our member organisation to host and share their work. This is a good chance to make links with similar organisations, build network to increase your impact.

Your logo on our website
As a member your logo and key information will appear on our website which is a go-to resource for stakeholders, industry and the general public when looking for information or collaborators.

Building Rare Resilience
We have so far run four rounds of our ‘Building Rare Resilience’ Programme, which is offered to all staff and volunteers working for Genetic Alliance UK member organisations. Collaborating with RaremindsCIC (a not-for-profit Community Interest Company specialising in providing professional counselling and wellbeing resources to rare disease organisations) we offer a psychotherapist facilitated 12-week group programme to support followed by monthly group sessions to build emotional resilience. Participants have the opportunity to ‘learn to look after themselves when supporting others’, and learn how to apply emotional resilience in patient leadership and/or support roles.

‘As a result of these meetings, our small group became really connected to each other so that when the course finished we continued off our own backs to meet weekly and just support each other. We have laughed, cried, celebrated grandchildren being born, talked about our own anxieties, things that affected not only our communities but our families and our personal lives. 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.’

Participant from Building Rare Resilience
MEMBERSHIP FEES 2022/23

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* Membership runs from 1 April to 31 March. Members joining throughout the year will incur pro-rata membership fees.