

JOB DESCRIPTION

Director of Engagement and Impact

Employer:	Genetic Alliance UK
Based at:	This is a UK-based role. Genetic Alliance UK's team is home-based The post-holder will be required to travel for occasional events, meetings with colleagues and team away days
Line manager:	Chief Executive
Term:	Between full time 1.0 FTE, 35 hours a week and 0.8FTE, 28 hours a week Flexible working with core hours of 10am to 4pm, including a one hour unpaid break, with remaining hours worked flexibly A permanent contract will be awarded after successful completion of a six month probationary period
Salary:	£55,167 to £63,654 with new starters normally appointed to the beginning of the range (this will be pro-rated for those that do not work full time)
Benefits:	Pension (5% employers, 3% employee); 25 days leave plus bank holidays plus full Christmas and New Year period office closure

About us

Genetic Alliance UK is an alliance of over 220 charities and support groups working together to improve the lives of people in the UK with genetic, rare and undiagnosed conditions.

Around 3.5 million people in the UK are affected by rare conditions, which are individually rare but collectively common.

We campaign for timely diagnosis, better coordinated care, and improved screening, testing, services and treatment. Our members and the people they support are at the heart of everything we do.

'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

'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

Genetic Alliance UK

contactus@geneticalliance.org.uk

www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

We are the national host for the annual Rare Disease Day and run two flagship projects:

- Rare Disease UK, the national campaign for the implementation of the UK Rare Diseases Framework and organiser of Rare Disease Day in the UK.
- SWAN UK, the only dedicated support network in the UK for families of children with undiagnosed genetic conditions.

Role

This new leadership role within the Senior Management Team (SMT) will enhance Genetic Alliance UK's impact by strengthening our relationship with our members and improving stakeholder communications through a strategic approach.

Genetic Alliance UK's strong reputation and network of external stakeholders is largely built on the successes of both the Policy and Public Affairs Team and the Research Team. These successes rely on the support of our members, and are amplified by the work of our Communications Team. By providing strategic oversight of relationships with our members, wider partners, and of our communications, this role will be central to increasing the impact of the whole organisation. This impact will be further enhanced by the post-holder taking a strategic view over how the prolific outputs of the Research Team and the Policy and Public Affairs Team are integrated into a programme of communication with all of our stakeholders.

Additionally the post-holder will be asked to fulfill an additional SMT responsibility with respect to culture and development of the team. These should support a positive and collaborative working culture, and provide a light-touch but meaningful framework for staff performance, development and wellbeing, helping the whole team to work well and feel supported. Genetic Alliance UK has a small team and divides wider senior duties among SMT. This duty should be compatible with the skillset of the ideal candidate as it relates to communication skills and relationship-building, as well as process related skills commensurate with this level of responsibility in a third sector organisation. As part of this duty the post-holder will own the relationship with our external HR provider. We do not expect an HR professional to apply for this role.

Engaging our members and wider stakeholders

- Direct and oversee the development of our approach to working with more than 220 diverse member organisations, ensuring they are offered new opportunities to share our platform and engage with our work.
- Direct and oversee the move from a 'few sizes fit all' approach to working with our members to a more comprehensive approach to inclusion.
- Grow our membership and broader audiences in a sustainable way that recognises the diversity of the UK rare condition community.
- Ensure systems and processes enable high-quality member experience, engagement and data use.
- Work with the Policy and Public Affairs Team to ensure our members are fully involved in campaigns such as Rare Disease Day, providing maximum impact.
- Work with the Research Team to ensure as many members as possible feel involved in research opportunities.

- Provide operational oversight of the SWAN UK project to ensure high standards, project delivery and safeguarding compliance.
- Contribute to the work to find a long-term home for the SWAN UK community and play a role in change management to ensure that the community is well-supported through this process.

Delivering impact through effective communications

- Provide strategic leadership to deliver coherent and cohesive communications from across the organisation to our wide range of stakeholders, reflecting our ambition and amplifying our impact.
- Improve consistency and planning across organisational communications activity.
- Take a strategic approach to balance approaches to communicating about:
 - Policy outputs
 - Public affairs activities
 - Research team outputs and activities
 - Urgent messaging responding to government or media events
 - Our members' activities
- Supporting the whole team to collaborate on effective communications to ensure maximum impact and deliver accurate communication on complex topics.
- Direct and oversee the organisation's relationship with individuals with rare conditions.
- Ensure the organisation's communications tools support income generation activity.

Fostering internal development and culture

As a member of SMT, take on a particular responsibility for processes to secure, foster and build the existing collaborative, cooperative, supportive and high-achieving culture in the organisation. This element of the role should be around 20% of working time. (As a small team, each SMT member takes on extra internal senior administrative duties, such as finance or data oversight.)

- Select, implement and oversee staff development systems, performance review processes, and cultural alignment.
- Select, implement and oversee performance and development frameworks for staff that align with organisational values.
- Ensure necessary updates to the staff handbook and internal policies in collaboration with SMT.
- Build on the supportive culture within the organisation to create sustainable staff training and development practices.
- Promote wellbeing and support inclusive working culture across the remote team environment.
- Liaise with external HR providers to keep our HR function and processes up to date.
- Disseminate project management approaches, proportionate reporting and internal communication processes to support frequent collaboration within a small team.

Team oversight

- Provide line-management for the Head of Membership and Communications .

- Oversee a team comprising Head of Membership and Communications, Communications and Engagement Manager (SWAN UK), and two posts to be filled: a communications officer and a project support officer.

Senior management

As part of the Senior Management Team (comprising this role, Director of Research and Chief Executive) contribute to the successful running of the charity by:

- Overseeing delivery of the strategy and reporting on its implementation to the Board of Trustees.
- Contributing to financial oversight of project budgets, team-members and activities within the remit of this post, including banking duties.
- Work with the Board of Trustees to ensure compliance with legal and regulatory requirements.
- Prepare and present papers to the Board of Trustees.
- Foster a positive and inclusive workspace culture.
- Ensure day-to-day operations run smoothly and efficiently.
- Identify and troubleshoot problems and conceive solutions.
- Carrying out other duties as required.

Person Specification

Essential qualities, skills and experience

- Experience of senior leadership or management roles involving multiple stakeholders or partners, ideally in the voluntary, public, or health sector.
- Proven ability to lead change with sensitivity, transparency and strategic vision.
- Strong leadership and people management skills, inspiring and coordinating multidisciplinary teams.
- Exceptional written and verbal communication skills, including the ability to communicate complex issues clearly.
- Experience in growing and sustaining membership or audience engagement.
- Expertise in stakeholder engagement strategies.
- Experience building positive, collaborative workplace culture.
- Advanced strategic communications skills, including campaign planning, coordinating outputs across teams, and ensuring consistent messaging across multiple platforms.
- Ability to use data and CRM systems to inform decision-making and measure engagement.
- Strong project management skills with the ability to prioritise and deliver multiple initiatives.
- Excellent interpersonal and communication skills, written and verbal, with the ability to convey complex issues clearly.
- Demonstrated ability to work collaboratively in hybrid or remote settings while making clear, timely decisions.
- Commitment to equity, diversity, and inclusion.
- Solutions-focused, adaptable, and aligned with Genetic Alliance UK's mission.

Desirable qualities, skills and experience

- Experience in membership-based or support-focused organisations, ideally within the health, research, genetic, or rare condition sectors.

- Strong understanding of the UK health landscape, including NHS structures and the rare condition charity sector.
- Experience growing membership or audiences sustainably and in line with organisational values.
- Familiarity with safeguarding in community engagement contexts.
- Track record in designing and embedding performance systems or staff development processes.

Additional requirements

- Ability to work occasional evenings and weekends.
- Willingness to travel within the UK occasionally.