

Dear Candidate

Thank you for your interest in becoming the next Chief Executive at Genetic Alliance UK. We're seeking someone to inspire and lead our talented and experienced team of staff following a period of major change at the charity.

### **About Genetic Alliance UK**

Genetic Alliance UK is an alliance of over 230 charities and support groups. We are a small charity with a 30-year track record of working together to improve the lives of people living with genetic, rare and undiagnosed conditions. We run two long-standing projects, Rare Disease UK and SWAN UK (syndromes without a name). You can find out more about our work and new five-year strategy at [geneticalliance.org.uk](https://geneticalliance.org.uk).

### **About rare, genetic and undiagnosed conditions**

While individually rare, these conditions are collectively common and affect around 3.5 million people in the UK. Genetic, rare and undiagnosed conditions are often life-limiting and life-threatening. Seven out of 10 rare diseases affect children, and sadly more than three out of 10 children with a rare disease die before their fifth birthday. People living with genetic, rare and undiagnosed conditions and their families can face a lifetime of complex care. They need vital support from the NHS, social care, education services and charities – us and our members – to live their lives to the full.

### **About this role**

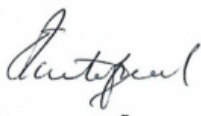
You will be a credible senior leader who listens and learns from the views of our members, supporters and partners, and builds on the high profile and strong reputation of Genetic Alliance UK. If you have the drive, energy and experience to lead our organisation towards achieving our ambitious strategy for the genetic rare and undiagnosed community then we would like to hear from you.

### **How to apply**

Please send a CV and written statement in support of your application to [ceo.recruitment@geneticalliance.org.uk](mailto:ceo.recruitment@geneticalliance.org.uk) by **17:00 on Monday 1 July 2024**. First round interviews will take place by Zoom on 10 and 11 July. We will interview a maximum of two final candidates face-to-face in London on 17 July.

For an informal conversation about the role, please contact our current Chief Executive Louise Fish ([louise.fish@geneticalliance.org.uk](mailto:louise.fish@geneticalliance.org.uk)) and/or Chair Elizabeth Porterfield ([chair@geneticalliance.org.uk](mailto:chair@geneticalliance.org.uk)).

Yours



Elizabeth Porterfield, Chair of Board of Trustees

# JOB DESCRIPTION

## Chief Executive

<b>Job title</b>	Chief Executive
<b>Salary</b>	£65,000 to £70,000 depending on experience
<b>Responsible to</b>	Chair of Trustees, Genetic Alliance UK
<b>Responsible for</b>	Director of Policy Director of Research Head of Corporate Partnerships Head of Membership and Communications External finance and HR suppliers
<b>Hours</b>	35 hours per week (FTE 35 hours per week), flexible working available
<b>Term</b>	Permanent
<b>Notice period</b>	Notice period of three months. This post is subject to a six-month probation period
<b>Location</b>	Home-based anywhere in the UK
<b>Benefits</b>	Generous employer pension contribution. Annual leave allowance of 25 days plus bank holidays and office closure between Christmas and New Year. Flexible working patterns. Access to employee support scheme.

### About this role

The Chief Executive will inspire and lead our talented and experienced team of staff following a period of significant change. You will lead on delivery of the charity's ambitious new five-year strategy and demonstrate the impact of our vital work. You will work closely with the Chair and Board of Trustees to deliver strong governance and mitigate organisational risk. You will drive business development and grow our income so we can deliver the strategy and rebuild our reserves after a challenging period. You will lead on the annual business planning and budgeting process, and maintain a rigorous approach to financial planning and forecasting. You will act as an ambassador and senior spokesperson to sustain the high-profile and strong reputation of Genetic Alliance UK, alongside senior management team colleagues.

## **Key responsibilities**

### **Strategy delivery and impact measurement**

- Lead the delivery of the charity's five-year strategy (2024-2029) to fulfil the mission, aims and values of the organisation, ensuring impact and progress are measured, monitored and reviewed at regular intervals.

### **Business development**

- Secure income from a wide range of sources to deliver the five-year strategy and rebuild the charity's reserves.
- Identify, evaluate and prioritise new business and income generation leads.
- Build and manage strategic relationships with partners (such as Department of Health and Social Care, LifeArc and Genomics England), large foundations and trusts (such as the National Lottery), companies, high net worth individuals (HNWIs) and philanthropists.
- Develop successful proposals to secure new core and project funding.
- Identify and drive income growth across membership, industry supporters, corporate partners, community fundraising and individual giving.
- Oversee trusts and foundations pipeline and commission external freelance support to draft bids as needed.

### **Operational management**

- Develop and implement an annual business plan to support delivery of the five-year strategy and prioritise the work of the team.
- Develop and implement an annual budget alongside a longer-term financial forecast that enables the Board to make informed decisions about the charity's sustainability and progress in rebuilding its reserves.
- Provide sound financial management and control across all business activities, working closely with the external finance provider
- Maintain effective HR practices across the charity and ensure compliance with all HR legislation, working closely with the external HR providers.
- Develop and implement strong processes for project planning, management and monitoring.
- Review the charity's current IT systems and make recommendations on whether change is needed to improve operational effectiveness.
- Act as the charity's Data Protection and Safeguarding lead.
- Provide senior oversight for the SWAN UK network.

### **Governance**

- Ensure the Board receives quarterly reports on the strategic and operational objectives of the charity, including monitoring performance against the five-year strategy, annual business plan and budget.
- Ensure the Board are advised of potential and current risks and the steps being taken to mitigate them.
- Ensure appropriate sub- committees are in place and operate effectively to support the charity (currently the Finance and Governance Committee, and People and Policies Committee).

- Lead on producing the Annual Report and Accounts and arranging the Annual General Meeting, working closely with the external finance providers, auditors and Head of Membership and Communications
- Act as or work closely with the designated Company Secretary, ensuring the Board and charity operate in accordance with the Articles of Association and meet all legal and regulatory requirements.

### **Internal leadership and line management**

- Provide effective leadership to the Senior Management Team and Management Team and inspire, motivate and be responsible for the overall development of the staff team, cultivating a positive and supportive working environment.
- Foster a culture of equality, diversity and inclusion.

### **External leadership**

- Maintain and strengthen our position as a credible voice for people affected by genetic, rare and undiagnosed conditions
- Provide leadership and represent the patient voice across all four nations of the UK within the genetic and rare diseases environment, ensuring strong relationships with stakeholders including governments, politicians, the media, the NHS, researchers and research funders, clinicians, and life science industry partners.
- Ensure all aspects of our work reflect the views of our members and relevant stakeholders, promoting a culture of collaboration.
- Act as an ambassador and a spokesperson for the charity at high profile events and in the media, alongside the Director of Policy and Director of Research.

## **Person specification**

### **Education**

- Educated to degree level or postgraduate level or equivalent experience.
- Evidence of continued professional development.

### **Essential qualities, skills and experience**

- Strategic thinker with excellent problem-solving, decision-making and analytical skills.
- Able to demonstrate a positive approach and champion cultural and organisational change.
- Strong support for the strategic aims, objectives and values of Genetic Alliance UK.
- Excellent interpersonal skills and ability to communicate complex ideas to staff and a wide range of stakeholders and public audiences.

- Leadership experience at a senior level in a complex environment, ideally with experience in the health, policy or research sectors.
- Demonstrable resilience working in a challenging environment for a period of time with proven experience of inspiring and motivating staff.
- Experience of delivering multi-year organisational strategies and demonstrating their impact.
- High level of business development and financial acumen, with strong track record in business development through securing new and growing existing income generation channels.
- Demonstrable experience of delivering strong governance and monitoring, managing and mitigating organisational risks.

### **Desirable qualities, skills, qualifications and experience**

- Strong understanding through professional or personal experience of rare, genetic or undiagnosed conditions.
- Experience of working within a membership organisation.
- Experience of working in the health and social care sector.
- Experience of working in a small charity.
- Experience of managing external providers delivering finance, HR and legal services.

### **Additional requirements**

- Able to work occasional evenings and weekends
- Willing to undertake occasional travel in the UK and in Europe.