

JOB DESCRIPTION

Engagement and Support Officer - Rare Resources Scotland

Job title: Engagement and Support Officer - Rare Resources Scotland
Employer: Genetic Alliance UK
Based at: Home based with travel within Scotland.
Line Manager: Head of Scotland and Public Affairs
Terms: (0.8 FTE), 6 months fixed term
Salary: £13,859
Closing date: 17:00 on Wednesday 20 August 2025

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: A campaign focused on making sure the new UK Rare Diseases Framework is as successful as possible, and to ensure that people and families living with rare conditions have access to a final diagnosis, coordinated care and specialist care and treatment.

SWAN UK: The only dedicated support network in the UK for families affected by a syndrome without a name – a genetic condition so rare it often remains undiagnosed.

ABOUT THE ROLE:

In this vital role, you'll drive engagement and create a supportive community for families in Scotland impacted by genetic, rare, and undiagnosed conditions. Collaborating closely with our Head of Scotland and Public Affairs, you'll be instrumental in delivering a groundbreaking pilot project that offers new support to these families. This is a unique chance to work directly with those affected by genetic, rare and undiagnosed conditions, expand your professional networks and help deliver a brand new pilot support service.

Key responsibilities:

Assist with the development of Scotland-specific support and information services for people affected by genetic rare and undiagnosed conditions.

- Deliver a programme of in person and online outreach activities and events (including well-being activities and information events) to engage with people affected by genetic, rare and undiagnosed conditions.
- Disseminate and promote our early intervention information toolkit - Rare Resources for Scotland.
- Assist with the facilitation of Genetic Alliance UK's 'Contact Us' information service.
- Work in partnership with key local organisations and services to deliver holistic support.

Raise awareness of genetic, rare and undiagnosed conditions.

- Be the local point of contact for enquiries.
- Help develop relevant and high-quality information to increase engagement and understanding of the impact of genetic, rare and undiagnosed genetic conditions.
- Network with local services and organisations to educate local professionals.
- Support the delivery of Scotland-based activities to promote Rare Disease Day.
- Recruit and support Scottish volunteers from the rare and undiagnosed community to share their stories, be media volunteers and take an active role in our outreach and policy activities.

Assist with the monitoring of our work against specified project outcomes.

- Maintain records of activities and the impact of our work.
- Help recruit participants to take part in the project evaluation.

Any other tasks as reasonably required by Genetic Alliance UK, including some evening and weekend work involving overnight stays.

Person specification

Education and qualifications

- Graduate level or equivalent experience.

Essential qualities, skills and experience

- An empathetic and compassionate attitude.
- Strong networking and relationship building skills.
- Experience of working in a similar role developing information and supporting people affected by health conditions.
- Goal-orientated with the ability to respond proactively to changes in circumstances.
- Methodical approach with attention to detail and ability to develop and implement efficient working practices and processes.
- A flexible, ideas driven approach to problem solving.
- Confident communicator with excellent written and verbal communication.
- High level of IT literacy with experience of social media platforms including Facebook, Twitter and Instagram.
- A friendly yet professional approach to meeting professionals and families and facilitating groups.
- Ability to work occasional evenings and weekends and occasionally travel in the UK, including some overnight stays.
- A commitment to the aims and objectives of Genetic Alliance UK and SWAN UK.

Desirable qualities, skills and experience

- Experience or knowledge of genetic, rare and undiagnosed conditions.
- Experience of working with families of disabled children.
- Experience of working with volunteers in a paid or voluntary capacity.
- Experience of organising events.
- Knowledge of the Scottish education, health and social care system.

HOW TO APPLY

To apply please email recruitment@geneticalliance.org.uk with your CV and a cover letter by 17:00 on Wednesday 20 August.

- In your cover letter please outline your experience, why you are interested in this role, your preferred hours of work per week and how you meet the person specification.
- Please note that applications which are generic cover letters or CVs without covering letters will not be considered.

Candidates selected for interview will be contacted by Friday 22 August 2025.

The interview will be held via Zoom on Friday 29 August 2025.