

JOB DESCRIPTION

Senior Policy and Research Officer

Job title: Senior Policy and Research Officer

Responsible to: Director of Policy

Salary: £28,000 per annum

Term: Permanent with six month probationary period

Location: Home-based with occasional travel

About Genetic Alliance UK

Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic, rare and undiagnosed conditions. We are a membership organisation made up of over 200 patient groups and we aim to upskill our members, bring knowledge and advice, and unify their voice around key policy issues that affect the patient community. We are experts in health policy and have a team of in-house academics who conduct research, and support our community to engage with research, into the effects of living with genetic, rare and undiagnosed conditions.

We have established partnerships with key organisations at the forefront of innovation in rare and genetic healthcare, including LifeArc, Cell and Gene Therapy Catapult, the Department of Health and Social Care, and Genomics England. We actively support external research and innovation across the field of genomic medicine, and raise awareness within the wider public. We have two long-standing projects:

Rare Disease UK is a campaign that was established to push for the creation and implementation of UK-wide policy to meet the needs of people affected by rare conditions. Rare Disease UK is also the official organiser of the international health awareness campaign, Rare Disease Day, for the UK.

SWAN UK (syndromes without a name) is the only dedicated support network in the UK for families that have a child or young adult with an undiagnosed genetic condition.

About the role

We are seeking a personable and analytical individual with the ability and skills to support and build Genetic Alliance UK's policy and research reputation. We are known for driving excellent and expert policy and research work through engagement with our member organisations and people living with genetic, rare and undiagnosed conditions. The role will be working directly with our members and our strategic partners on a wide-range of topics including genomics, health service research, UK rare disease policy, innovative medicines, health technology appraisal of treatments for rare conditions, reproductive choice and much more. The successful candidate will be able to demonstrate a strong interest in supporting people living with genetic and rare conditions and the

Genetic Alliance UK

contactus@geneticalliance.org.uk
geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

organisations that work for them. We think this role is an excellent opportunity to gain experience and would be delighted to receive applications from enthusiastic candidates with the skills to deliver this important role.

Purpose of the role

- To ensure our member organisations and people living with genetic, rare and undiagnosed conditions are engaged in policy and research that affects them.
- To collaborate with colleagues to ensure our messages are evidence-based, accurate and consistent.
- To meet with and support our member organisations to engage in policy and research.

Key responsibilities

Communicating

- Represent Genetic Alliance UK and deliver Genetic Alliance UK's messages at working groups and consultative events.
- Support the production of detailed policy reports where necessary.
- Contribute policy perspectives to the preparation of public affairs briefings.

Informing and involving

- Write good quality consultation responses, ensuring members of the team, member organisations and other relevant stakeholders with appropriate expertise have the opportunity to contribute.
- Participate in activity, such as webinars, video production and face to face meetings to educate and inform our membership on policy and research issues.
- Coordinate the production of condition specific statements for PGD regulation by the Human Fertilisation and Embryology Authority, through an established member consultation process.
- Enable individuals and member organisations to participate in 'patient and public involvement and engagement' in research (PPIE) through organising events (webinars, meetings), taking account of the needs of and supporting those taking part.
- Support initiatives such as the development of public-facing materials to promote good PPIE practice

Collaborating

- Advise and inform members of the Genetic Alliance UK staff team on policy issues relating to any aspect of their work.
- Work with the communications team to ensure that our communications on policy and research topics are accurate.

Other

- Any other duties as may reasonably be required.

Person Specification

Education and qualifications

- Educated to degree level or equivalent.
- High IT literacy and proficiency in relevant applications.

Essential qualities, skills and experience

- Experience in a health or medical research orientated policy team OR relevant post-graduate study.
- Excellent communication skills, both written and oral.
- Experience of stakeholder engagement
- Ability to write clear and logical documents.
- Ability to adapt writing style for a range of audiences.
- Ability to work both as part of a team and independently.
- Ability to meet agreed deadlines, prioritise workload and maximise the use of time.
- A can-do attitude to work, with enthusiasm and creativity.
- Attention to detail to all aspects of work.
- A commitment to the aims and objectives of Genetic Alliance UK.

Desirable qualities, skills and experience

- Appreciation of current issues in the rare condition and genomic healthcare policy world and their impact on patients and families.
- Appreciation of approaches to PPIE in research and the value of PPIE
- Knowledge of the NHS environment and medical genetics.
- Knowledge of the academic research environment.
- Experience of policy work at the devolved nation and/or European level. Experience of the voluntary sector.

Additional requirements

- To be able to work occasional evenings and weekends.
- Willing to undertake occasional travel in the UK and Europe.

Person Specification

To apply please email recruitment@geneticalliance.org.uk with your CV and a cover letter by the **end of Sunday 28 July** for the attention of Nick Meade, Director of Policy.

- In your cover letter please outline your experience, why you are interested in this role, your location and how you meet the person specification.
- Please save your documents as YourName.SPRO.CV and YourName.SPRO.CoverLetter and use SPRO Application as the email subject line.
- Please note that applications which are just generic cover letters or CVs without covering letters will not be considered.

Candidates selected for an interview will be contacted by close of business Thursday 8 August. Interviews will be held via zoom on Tuesday 13, Wednesday 14, Tuesday 20 and Wednesday 21 August. If you have a preference for one of these days please give details in your application.

Due to capacity restrictions we will not be able to provide feedback for candidates not selected for an interview. As the successful candidate will be handling sensitive health data and potentially

meeting vulnerable individuals, successful candidates will have to pass a disclosure and barring security check.

If you would like to discuss this role further please contact nick.meade@geneticalliance.org.uk.