

JOB DESCRIPTION

Senior Communications Officer

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:	Head of Membership and Communications
Term:	Permanent, hours: 28 hours per week (0.8 full time equivalent)
Salary:	£23,764 per annum (full time equivalent, £29,705)
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

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 role offers the chance to make a real difference by helping Genetic Alliance UK share our work more widely and connect more deeply with our community of members, supporters and partners. As Senior Communications Officer, you will be at the heart of our efforts to tell powerful stories, highlight our impact, and inspire support for people living with genetic, rare and undiagnosed conditions.

Most of your time will focus on communications: creating engaging, visual content for our digital channels, newsletters, website and campaigns, and helping us to raise the profile of the charity. Around a fifth of your time will focus on fundraising, supporting individual donors, community fundraisers and corporate partners, and helping us deliver light-touch campaigns that grow our income and supporter base.

You will also have the opportunity to work closely with our new Director of Engagement and Impact, supporting their leadership of membership and communications, and contributing ideas to strengthen how we engage all our audiences. We are looking for someone who enjoys producing creative, visual communications, generating ideas that drive engagement, communicating complex ideas clearly, and keeping content fresh across our platforms.

We are a small and collaborative team, so you will have the chance to work across all areas of the charity, handle enquiries, build your skills, and see the direct results of your work. If you are creative, motivated and keen to play a part in improving the lives of people affected by genetic, rare and undiagnosed conditions, we would love to hear from you.

Our approach to communications is evolving to meet the realities of today's digital and informational landscape. We are not looking for a traditional marketer, but for someone who sees communications as a form of advocacy – someone who is proactive, curious, and ready to explore new ways to connect people, evidence, and stories in service of our community. The right candidate will understand that clarity, trust, and empathy are as important as reach or metrics, and will help ensure that the voices of those affected by rare and genetic conditions remain visible and influential in a rapidly changing world.

Key responsibilities

Communications and Content

- Lead on drafting and disseminating Member News (monthly) and Genetic & Rare News (every quarter for donors and supporters).
- Manage public-facing social media channels (Twitter/X, Facebook, Instagram, LinkedIn, YouTube, Bluesky), ensuring engaging and accessible content.
- Manage website content (open source CMS systems like Wordpress and Drupal), working with external developers where needed, ensuring optimisation, accessibility, and fresh content.
- Source, synthesise and share stories and perspectives from our member and patient community, ensuring their voices are at the heart of our communications.
- Support campaigns such as Rare Disease Day, including creation of toolkits, promo packs and imagery for members and the wider community.

- Attend two to four conferences per year to raise awareness of Genetic Alliance UK with our stakeholders, including supporting an exhibition stand.
- Contribute creative ideas to strengthen content and help drive traffic and engagement across our platforms.
- Produce high-quality written and visual content (copy, infographics, digital assets) in line with brand and style guidelines.
- Where capacity allows, provide light design support for major projects (e.g. Impact Report, policy publications).
- Respond to general enquiries across our communication channels with the support of expert colleagues where necessary (email, phone, social media).
- Support colleagues with proofing, editing and formatting documents and assets.
- Assist with design, proofing and formatting of digital assets and publications.
- Contribute flexibly to wider team projects and events as required.

CRM and Data

- Ensure donor and supporter data is accurately recorded in the CRM system (Beacon).
- Run reports, analyse data, and use insights to inform communications and fundraising in collaboration with the Head of Membership and Communications.

Fundraising communications

- Draft regular fundraising content for our communications channels (social media, e-newsletters, website).
- Support light-touch fundraising campaigns, including Christmas and The Big Give, and highlight opportunities around Rare Disease Day and Undiagnosed Children's Day.
- Support corporate partnerships (donations, employee fundraising, sponsorship, pro-bono/in-kind).
- Maintain awareness of our legacy programme with partner Kwil, and explore light-touch in-memory giving options.
- Responding to ad-hoc requests around individual giving fundraising, sporting events and similar.

Person specification

Essential qualities, skills and experience

- Strong IT literacy, with experience using CRM systems and digital platforms (website, digital marketing, social media).
- At least two years' experience in a communications role, ideally within the charity, academic or non-profit sector.
- Proven ability to produce meaningful and accurate written content for a range of audiences, adapting tone and style for donors, supporters, members and wider stakeholders.
- Good design skills, with experience producing visual assets in line with brand requirements (using tools such as Adobe suite and/or Canva).
- Confident in managing and growing social media channels (e.g. Twitter/X, Facebook, Instagram, LinkedIn), including use of scheduling and analytics tools.
- Strong organisational skills, able to balance multiple priorities and deadlines while maintaining attention to detail.
- Ability to deliver against agreed objectives, including fundraising and engagement targets.

- Experience developing and maintaining positive relationships with supporters, donors, fundraisers, corporate partners or equivalent stakeholders.
- Excellent interpersonal skills, with empathy for the challenges faced by people affected by genetic, rare and undiagnosed conditions.
- A collaborative, flexible approach, able to work well both independently and as part of a small team.
- Enthusiasm, creativity and a proactive 'can-do' attitude.
- Commitment to the aims and values of Genetic Alliance UK.

Desirable skills and experience

- Experience of communications or fundraising in the health and social care sector.
- Experience of working in a small charity environment.
- Experience of working within a dispersed home-based team.
- Familiarity with data protection requirements relating to supporter data and use of open source CRM systems such as Drupal and Wordpress.

Additional requirements

- Willingness to undertake occasional UK travel.
- Ability to work occasional evenings and weekends.