



Ataxia UK Head of Fundraising and Communications

Information Pack

ATAxia

About Ataxia UK

Thank you for your interest in the role of Head and Fundraising and Communications at Ataxia UK, we hope that this information will enable you to understand what an exciting time it is at our charity, and that you will go ahead and apply to join our great team.

'Ataxia' is an umbrella term for a group of neurological disorders that affect balance, coordination and speech. There are many different types of ataxia that affect people in different ways. You can read about the different types of ataxia in our 'types of ataxia' section, or access a general overview of the condition in our "[Ataxia: what's that?](#)" leaflet. Anyone of any age can get ataxia, but certain types are more common in certain age groups. For example, people with Friedreich's ataxia (the most common ataxia) are usually diagnosed in childhood or adolescence.

The ataxias are rare conditions. Estimates from recent studies say that there are at least 12,000 adults and around 500 children in the UK with a progressive ataxia of which there are over 200 different forms. A few are treatable, but in most cases, there is no treatment or cure. Over the last 59 years of our existence, we have always supported research and put lots of effort into supporting those who are looking for treatments or cures.

Last year the USA approved the first drug for Friedreich's ataxia (FA), Skyclarys, and it is now going forward for approval in the UK. We will be closely involved in this as a patient voice for people with FA. As trials of potential treatments for the ataxias multiply, we are preparing for a new era in the work of Ataxia UK: as a channel for patient voices into the many drug approval processes that we hope will follow. This is affecting organisational priorities.

Likewise, our support services to people affected by the ataxias have entered a transformative phase following the obtaining of a 5-year grant from the National Lottery Community Fund to support the further development of our Helpline and Advocacy services in England and employ our first Specialist Ataxia Nurse to work with people affected by ataxia in January 2025, which will, give access to quicker diagnosis and other benefits.

The support that Ataxia UK provides to people affected by ataxia is made possible through the generous donations and fundraising of Friends and supporters, the grant giving of trusts and foundations, and in this era of drug discovery for the ataxias, also from pharmaceuticals which is now producing a shift in our fundraising priorities which will need to be managed by the new Head of Fundraising and Communications.

From information for people affected by ataxia to supporting our fundraising efforts, lots of what we do is fundamentally dependent on the strength of our communications, and this is also managed by this post.

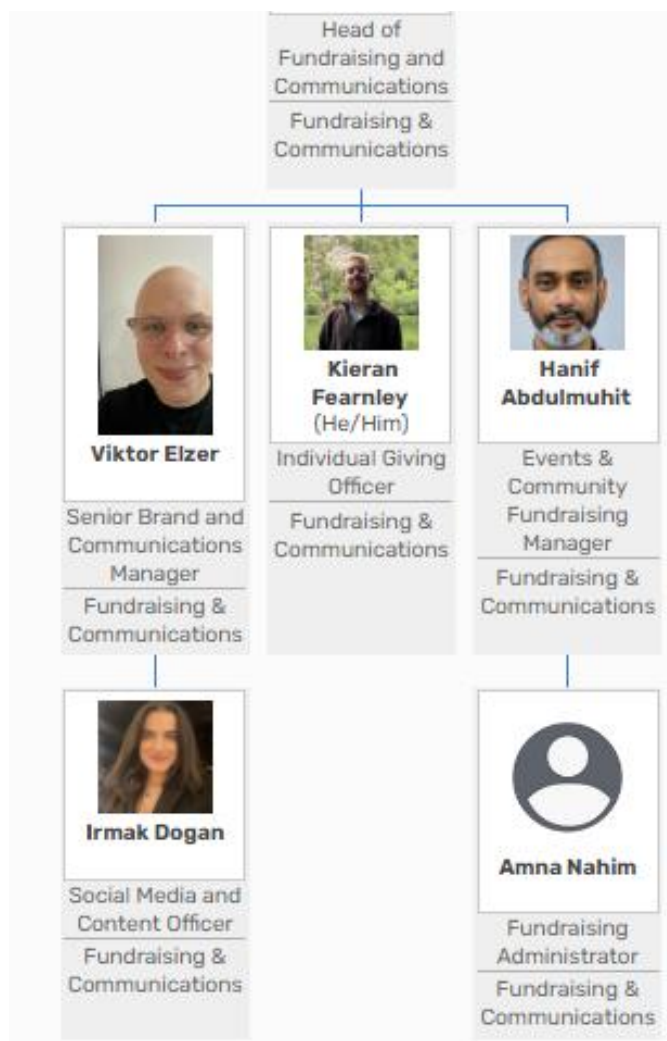
If you are prepared to rise to the challenge of this post, I very much look forward to hearing from you.

Sue Millman, CEO Ataxia UK



The role of Head of Fundraising and Communications

The Head of Fundraising and Communications is a member of our Senior Management Team, which also includes the Chief Executive, the new post of Chief Operating Officer, the Head of Research and Head of Services. As Ataxia UK continues to grow and its role evolves, the role of the SMT is becoming increasingly vital to the charity, ensuring our Strategic Plan is progressed through co-ordination and collaboration across the organisation.



The Fundraising Team comprises the Individual Giving Officer, whose role is evolving to embrace supporting the Head of Fundraising and Communications' work with major donors and trusts; and the Events and Community Fundraising Manager who manages the Fundraising Administrator who supports the work of the fundraising team.

Due to the rarity of ataxia our supporter base is relatively small, but there are opportunities to further develop our regular giving. The Big Give Christmas Challenge performs well with the support of committed pledgers.

Our legacy stream is consistent and usually produces around 10% of our income, with grant funding from Childlife, a joint venture with three other charities usually approaching 7.5% of income.

Our community is committed and active in local fundraising ventures, in which we support them. Our 5 London Marathon places are hotly contested, and we

support these and participants in other events. Since the pandemic we have found that Ataxia UK-led events don't attract the previous levels of participation and income, so we have paused these, but would be interested in re-starting them if we could make them work.

The Communications Team is headed by the Senior Brand and Communications Manager, who manages the Social Media and Content Officer. Among many other things, the team produces our quarterly supporter's magazine, a monthly e-newsletter, designs most of our outward facing publications, and manages the website.

One of the priorities in our next Strategic Plan will be the further development of our information services to people affected by ataxia. This team will have an important role to play in formulating and delivering our ambitions.

Ataxia UK's Strategic Plan for 2022-25 contains these ambitions:

- Improve access to specialist, integrated care (including mental health care), treatments and drugs for the ataxias
- Faster, accurate diagnosis
- Consistently maximise the impact of research activity leading to treatments and cures
- Enable greater access to services aimed at improving wellbeing and financial circumstances

Our Strategic Plan 2022-25 takes into account the impact of the changes brought about in many areas of life by Covid-19 and the current economic climate which is affecting disabled people more than the general public and exacerbating the serious poverty of a small but significant number of people affected by ataxia.

Some of the most significant actions we are taking to meet these objectives are:

- Establish a peripatetic Specialist Ataxia Nursing Service to accompany patients to appointments and support them in managing all aspects of their care.
- Continue to develop the Helpline and Advocacy Service and improve the support information held on the website.
- Revise the Medical Guidelines for the Treatment of the Ataxias and publish the 4th Edition.
- Increase the patient representation work we undertake in research projects.
- Increase the number of Accredited Ataxia Centres in the NHS to at least six.
- Support the drugs approval process in the UK.
- Utilise the All About Ataxia seminar model to develop other online information seminars.



Working at Ataxia UK

Our office is in Highgate. The closest tube station is Archway and then you can walk up Highgate Hill, or there are plenty of buses.

Most staff are employed under a hybrid working contract and come into the office 1 -3 days a week depending on their role/contract/working hours. Once a month we designate a day when as many people as possible come into the office to work together.

We offer a wide range of contractual benefits*

Annual Leave 25 days (plus Bank Holidays) rising by 1 day per year to 30 days. You can also take your birthday off!

Pension Employers' contribution of 5% to NEST

Maternity Policy Enhanced maternity pay package including

- 12 weeks full pay including statutory maternity pay
- 12 weeks at 50% pay including statutory maternity pay
- A further 15 weeks at statutory maternity pay
- Up to 13 weeks without pay.
- A total of 52 weeks maternity absence.

Adoption leave entitlement is the same as the maternity policy (without statutory maternity pay).

Flexi-time Procedure We aim to ensure our efficiency whilst recognising that supporting a flexible working environment is a key factor in attracting and retaining committed employees.

Employee Assistance Scheme All staff have access to our Employee Assistance Scheme provided by Wisdom. There is an online wellbeing portal accessed via an app. A few of the items this scheme offers are:

- 24/7 telephone helpline
- Live chat with counsellor
- Financial & Legal advice
- Mental Health First Aider training
- Medical information
- Rewards & Discounts & much more...

Eye test & Glasses policy Ataxia UK covers the cost of an eye test, up to £30. In addition, staff claim up to £130 every two years towards the cost of glasses.

Cycle for Work

We have joined up with [bike2workscheme.co.uk](https://www.bike2workscheme.co.uk) to offer a great bike to work scheme which contributes a 40% discount towards purchasing a bike or bike equipment. We encourage all staff to use public transport or cycling when getting to work, as part of our focus in reducing our carbon footprint. Click on the link below to see a 'how it works' video.

<https://www.bike2workscheme.co.uk/how-it-works>

The above is a precis of contractual benefits. For actual terms see Staff Handbook and Contract of Employment.



Job Description: Head of Fundraising and Communications

Salary:	£55,000 rising annually by 4 increments of £500 payable on 1 April (on completion of 12 months continuous employment in the preceding year).
Contract Type:	Permanent
Conditions:	25 days annual leave pro rata rising by one day per year to 30 days 5% contribution to a personal pension plan Employee assistance scheme Comprehensive flexible working policy Season ticket loan available Bike-2-Work Scheme Accredited Living Wage Employer Birthdays off
Hours	Full time, 35 hours per week. Some out of hours work may be required for which time off in lieu will be granted.
Location:	Hybrid – between home and Ataxia UK Office, Highgate, London N6 5JW with a minimum of 2 days per week in the office
Reporting to:	Chief Executive Officer
Direct Reports	Community Fundraising Manager Individual Giving Manager Senior Brand and Communications Manager

Role Overview

As a member of Ataxia UK's Senior Management Team (SMT), the Head of Fundraising and Communications plays a pivotal role in shaping and delivering the strategic direction of the charity. This includes active participation in SMT meetings, working closely with the Chief Executive and the other members of SMT to oversee the effective management of the charity.

- Contributing to the development of organisational strategies and policies.
- Representing the Fundraising and Communications Team in cross-departmental discussions and decision-making processes.
- Ensuring that all fundraising and communications activities reflect Ataxia UK's strategic objectives and uphold its values and reputation.

The postholder is responsible for developing and leading the fundraising strategy and activity, with a particular focus on major donor fundraising, whilst also overseeing all areas of fundraising and communications, ensuring integration, and fostering collaboration across departments.

Senior Management Team

1. Contribute to the strategic direction of Ataxia UK.
2. Participate in the governance and management of Ataxia UK, through senior management team meetings and projects.
3. Develop collaborative working relationships with other members of Ataxia UK's Senior Management Team and Board of Trustees, ensuring they are kept informed of the fundraising and communications team's strategy, progress and major achievements.

Fundraising – with a strategic emphasis on High Value Fundraising

1. Lead on Fundraising Strategy
Implement and further develop the existing multi-channel fundraising strategy with a particular focus on generating income through High Value Fundraising
2. Grow and develop Ataxia UK's income from High Value Fundraising income streams including major donors and corporate fundraising
 - a. build sustainable, long-term relationships that align with Ataxia UK's fundraising priorities and the creation of clearly defined, measurable targets
 - b. Manage high-level relationships with major donors, ensuring their contributions are recognised and cultivated for future support. Lead the development of strategies to increase the lifetime value of major donors
 - c. To develop a new ambassadors/patrons and celebrity boards and programmes.
 - d. Develop and manage a new effective and engaging mid/high value philanthropy programme and create ways of working and protocols for the identification of donors to the wider Ataxia UK supporter base.
 - e. Work with the Board of Trustees and existing Major Donors to map and engage new networks to generate prospects for the Major Donor strategy
 - f. To support the delivery of a new strategy for working with high profile individuals and influencers.
3. Supervise Individual Giving and Community Fundraising
 - a. Provide leadership and supervision to the Individual Giving Manager and Community Fundraising Manager, setting income targets and delivering strategic support
 - b. Ensure integration of fundraising efforts to enhance donor journeys and maximise giving opportunities across all streams.
4. Trusts and Foundations
 - a. Research, develop and produce a range of bids to charitable trusts and foundations, and occasionally to government departments and other appropriate organisations.
5. Develop Fundraising Tools and Materials
 - a. Oversee the creation of bespoke, high-quality materials that resonate with major donors and support broader fundraising activities
 - b. This includes printed materials, e-marketing, and web-based materials designed to engage various donor audiences effectively.

6. Compliance and Reporting
 - a. Ensure compliance with fundraising best practices, including data protection legislation and the Charity Commission's guidelines
 - b. Oversee the use of Raiser's Edge for recording, monitoring, and reporting on all fundraising activities
 - c. Provide comprehensive reporting to the Board.
7. Events and Presentations
 - a. Attend and represent Ataxia UK at relevant fundraising events, including those involving major donors
 - b. Deliver presentations to potential and existing donors to cultivate relationships and secure significant gifts.

Communications

1. Lead the Communications Strategy
 - a. Oversee the implementation of the Communications Strategy ensuring the strategy supports major donor fundraising and Ataxia UK's broader work
2. Supervise the Communications Team
 - a. Provide leadership and supervision to the Senior Brand and Communications Manager, setting clear performance targets and delivering strategic support
 - b. Ensure communications activity and strategy aligns with the broader fundraising and organisational goals
 - c. Provide direction on the production of materials that support fundraising, including publications, newsletters, and online content.
3. Digital and Social Media Engagement
 - a. Support the Senior Brand and Communications Manager to develop Ataxia UK's online presence, including the website and social media platforms, to ensure timely updates on research, services, and fundraising initiatives
 - b. Leverage digital channels to enhance engagement with potential and current major donors.
4. Media Strategy
 - a. Ensure consistent and proactive media engagement to raise Ataxia UK's profile
 - b. Oversee media relations efforts to ensure positive exposure across press, radio, and TV outlets, especially in connection to major donor fundraising events and campaigns
 - c. Work closely with Ataxia UK's celebrity patrons, managing their engagement and maximising their influence to enhance media visibility and impact for fundraising campaigns and key organisational events
5. Regulatory Compliance in Communications
 - a. Ensure all communications comply with regulatory requirements and align with Ataxia UK's principles

Management

1. Team Leadership

- a. Provide strong leadership to the Fundraising and Communications Team, with a focus on fostering a high-performance culture.
 - b. Oversee the recruitment, management, and development of staff, ensuring the team delivers on ambitious major donor and fundraising targets.
2. Supervision and Appraisal
 - a. Conduct regular supervision and appraisals of direct reports in line with Ataxia UK's procedures.

General

1. Representation
 - a. Represent Ataxia UK at events and conferences as required.
2. Budget Management
 - a. Prepare and manage budgets for all areas of responsibility, with a focus on ensuring cost-effectiveness and delivering income growth High Value Fundraising
 - b. Ensure income and expenditure are in line with Ataxia UK's financial procedures.
3. Reporting and Development
 - a. Write detailed reports and presentations for the Board of Trustees, reflecting on major donor fundraising progress and broader team achievements
 - b. Attend Board meetings as required.
 - c. Service the Fundraising and Communications Group
4. Professional Development
 - a. Engage in professional development and training opportunities to keep abreast of sector trends, particularly in major donor fundraising and communications.

Note: This job description sets out the duties of the post at the time it was drawn up. Such duties may vary from time to time without changing the general character of the duties or the level of responsibility entailed. Such variations are a common occurrence and cannot themselves justify a reconsideration of the grading of the post. Ataxia UK reserves the right to update the Job Description from time to time to reflect these changes in or to the post after consultation about any proposed changes.

Person Specification:

When writing your cover letter, please specifically address the points as listed below.

Essential criteria

- Significant experience (3+ years) in, and experience of, Philanthropy programmes/Major Donor fundraising, raising gifts or donations of 6 or 7 figures.
- Experience in developing and implementing successful major donor strategies.
- Strong communication and negotiation skills, with a track record of significant gifts from major donors and stakeholders.
- Experience in managing budgets and delivering growth in fundraising income.
- Strong leadership and team management skills, with the ability to inspire and develop a high-performing team.
- Excellent networking skills, with experience in building relationships with senior-level stakeholders.
- Knowledge of relevant fundraising legislation, including Data Protection and how it relates to fundraising and communications and the Fundraising Code of Practice.
- Support for the ethical use of animals in medical research.

Desirable Criteria

- Membership in the Institute of Fundraising or strong networking connections within the sector.
- Experience of using Raiser's Edge.
- Experience in fundraising for medical research or similar sectors.
- Professional qualification in fundraising

To Apply for this Post

Please see our advert on Charity Job apply via the site.