



Volunteer Role Description

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. Ataxia is a rare condition, with approximately 10,000 adults and 500 children living with a progressive form of ataxia. Ataxia UK is the only leading national charity for people affected by any type of ataxia. We fund research into finding treatments and cures, and offer advice, information, and support to people affected by the condition.

Volunteer Role: Clinic Volunteer (in person)

Supported by: The Services Team; Community Programme Officers and Helpline Officers

Where: London Ataxia Clinic in Queens Square

Commitment: One day per month in person for 3-5 hours for 6 months subject to your availability

Training: As part of your volunteer onboarding - Equality & Diversity Training, Safeguarding, Health & Safety, A practical guide to GDPR. Role shadowing with already existing volunteers.

Objectives:

Receiving a diagnosis may feel isolating - our clinic volunteers provide a **listening ear, peer support & non-clinical advice** to those that have been newly diagnosed after their appointment with the consultants at the ataxia clinic.

The volunteers will also provide support and more information to those that may have had a diagnosis for a long time but would like to learn more about the condition or the services on offer at Ataxia UK.

Our Clinic volunteers help signpost those needing more support to the Ataxia UK Helpline.

Ataxia UK, 12 Broadbent Close, London N6 5JW Office 020 7582 1444 Helpline 0800 995 6037
volunteering@ataxia.org.uk

www.ataxia.org.uk Ataxia UK is a Charity registered in Scotland (SC040607) & England & Wales (1102391); & Limited Company (4974832)

Personal qualities:

- Lived experience of ataxia (as diagnosed with or as a family or friend affected by ataxia)
- If diagnosed, to have been so for at least 1 year or have been a Friend of Ataxia UK for at least 1 year
- Willingness to learn
- Be knowledgeable about the current work Ataxia UK is doing and friendly when representing Ataxia UK
- Good interpersonal skills
- Are committed and reliable
- Willingness to travel to the London Hospital
- Be a confident listener & communicator, as you will be working with a wide range of different people

Tasks and activities:

- To abide by the rules, policies & procedures set out by the Hospital.
- To attend Clinic days at the Ataxia UK London Clinic once per month as agreed upon
- To meet with patients and their supporters who have been referred by the ataxia clinic team after their clinic appointment in the hospital
- Provide a **listening ear, peer support and non-clinical advice** to those who have been newly diagnosed
- Provide support and information about Ataxia UK to the patients and encourage them to join Ataxia UK
- Carry out surveys with patients about their quality of care and support and feedback about the ataxia clinic
- Signpost the patients to the Ataxia UK Helpline when more information is needed/ Advocacy Services needed
- Keep up-to-date with the services available through Ataxia UK as well as the charity itself
- Sign up to the monthly e-newsletter, quarterly magazine & services e-newsletter
- Attend quarterly volunteer supervisions online with the Services Team
- Submit travel costs to the Services Team to process for reimbursement

In return, as an Ataxia UK volunteer, we will offer you:

- Induction learning
- Great addition to your CV
- Make a real difference for people living ataxia
- Quarterly Supervisions with the Ataxia UK Services Team

For further information and enquiries:

volunteering@ataxia.org.uk