



Ataxia UK accredited Specialist Ataxia Centres – London

Ataxia UK accredited Specialist Ataxia Centres are centres of excellence, where people with ataxia receive the best possible quality of care and a co-ordinated service combining diagnosis, treatment, support and research. They have been set up in direct response to needs identified by people affected by ataxia, as well as clinicians with expertise in the condition.

To achieve accreditation, centres have to comply with criteria devised following consultation with patients with ataxia and clinicians with an expertise in ataxia, to provide 'excellence of care for the diagnosis and management of the ataxias, and access to a wide range of integrated services, as well as links to research programmes'.

The London Ataxia Centre

The London Ataxia Centre at the National Hospital for Neurology and Neurosurgery in London is the first Ataxia UK accredited Specialist Ataxia Centre in England. It brings together a team of specialists, with expertise in the diagnosis, management and research of all forms of ataxia and offers patient centred care for all people living with ataxia.

The London Ataxia Centre comprises three consultant neurologists and a paediatric consultant neurologist with specialist expertise in ataxias, two ataxia clinical nurse specialists, an ataxia research nurse and specialist ataxia occupational therapist, speech therapist and neuro-physiotherapist. There is also a team of medical researchers and a research trial co-ordinator who attend clinics.

Four types of clinics are currently offered, either as face-to-face or remote appointments where appropriate and according to patient preference:

- Consultant-led general ataxia clinics
- An Interdisciplinary Therapy (IDT) clinic for the assessment and holistic management of patients with therapy requirements
- Nurse-led telephone and face-to-face clinics offering ongoing support and advice between outpatient appointments
- Paediatric ataxia clinic (London Children's Centre) - leads a translational research programme, primarily focused on the genetic basis of ataxias, particularly Friedreich's ataxia

Consultant-led ataxia clinic

Consultant-led general ataxia clinics run four times a week, supporting the investigation and monitoring of ataxia, and where appropriate, genetic counselling. This specialised service is available for all patients with a suspected or confirmed genetic ataxia or other degenerative cerebellar ataxia. Referrals are accepted from neurologists and GPs throughout the UK. The clinic provides:

- Long appointments – 45 to 60 minutes for new patients, 30 minutes for follow-up.
- Continuity of care – patients see the same Neurologist.
- Referral to an interdisciplinary therapy clinic (see below)
- Opportunity to be reviewed on the same day in parallel Neuro-ophthalmology, Uro-Neurology and Audio-vestibular clinics.
- Close links with primary, community and secondary care services for shared care and education on the ataxias.
- Support both during and between clinic visits via the ataxia nurse specialists.
- Close links with the Neurogenetics Unit which allows the development of new genetic tests.
- Links with a number of other specialists at the National Hospital for Neurology and Neurosurgery with expertise in managing ataxia related symptoms, and established referral pathways in the following disciplines:
 - Cardiology
 - Neuropsychiatry
 - Neurophysiology
 - Gastroenterology
 - Dietetics
 - Autonomics
 - Orthotics
 - Vocational Rehabilitation
 - Group exercise clinics
 - Complex spasticity
 - Neuropsychology
 - Neurological and spinal surgery
 - Orthopaedics
 - Audio-vestibular

Interdisciplinary Therapy (IDT) Clinic

The IDT clinic comprises the lead consultant neurologist specialising in ataxia, an occupational therapist, physiotherapist and speech and language therapist with particular expertise in adult neurological rehabilitation. The clinic runs weekly (either face-to-face or via video), and provides specialist assessment focussing on the functional impact of ataxia in relation to everyday activity. The aim of the clinic is to provide a comprehensive assessment of patients' needs, offer specialist advice and optimise access to community services. Patients may then be referred locally if appropriate, or followed up for therapy needs at the National Hospital for Neurology and Neurosurgery.

Nurse-led clinics

Nurse-led clinics may be offered between appointments with the neurologist for additional support for symptomatic management and advice, information relating to welfare and benefits, and referral to other disciplines or agencies. The Clinical Nurse Specialists work within the multi-professional team and will ensure that any concerns are communicated to all necessary members. Please note that the specialist nurses are only able to provide clinical advice and support for people under the care of a consultant neurologist at the London Ataxia Centre. Anyone interested in accessing the expertise of the London Ataxia Centre should ask their doctor or neurologist for a referral (see below referral information).

To read our interview with the specialist ataxia nurse at the London Ataxia Centre, click [here](#).

Paediatric ataxia clinic

The Paediatric Ataxia Clinic leads a translational research programme, primarily focused on the genetic basis of ataxias, particularly Friedreich's ataxia. They recognise the importance of clinical registries and gathering natural history data, so that when therapeutic trials can be offered, their service is "trial ready", and their patient data influences robust, safe trial design. In order to meet the research focus of the clinic, suitable referrals will be selected by the clinic team.

Involvement in research

The London Ataxia Centre participates in many of the principal international clinical and basic science research consortia, and some of the most significant interventional (drug/therapy) trials in ataxia. The centre is therefore able to offer up-to-date information on the current state of research and participation in international clinical trials and natural history studies.

The London Ataxia Centre is registered as the UK 'expert centre' for ataxias within the European Reference Network for rare neurological diseases (ERN-RND). European Reference Networks (ERNs) are virtual networks connecting healthcare professionals around Europe with expertise in rare diseases which allows them to discuss a patient's diagnosis and care, with their consent, via an online IT platform. The network also aims to develop a comprehensive database to better understand these conditions, and create a platform for testing potential treatments. Professor Paola Giunti is the UK representative on the board of the network.

Clinic team

Consultant Neurologists:

Professor Paola Giunti

Dr Michael Parkinson

Dr Rajith De Silva

Dr Shpresa Pula

Clinical Research Fellows:

Dr Hector Garcia-Moreno

Dr Martina Marconi

Clinical Nurse Specialists:

Suzanne Booth

Katarina Manso

Research Nurse:

Michelle Berin

Specialist Physiotherapist:

Rachel Higgins

Specialist Occupational Therapist:

Caroline O'Neill

Specialist Speech and Language Therapist:

Lucie Hogger

Following ataxia clinic visits patients have the opportunity to connect with a representative from Ataxia UK. The representatives have direct experience of ataxia and will offer emotional and practical support as well as information on the services Ataxia UK offers.

Referrals are accepted from GPs and neurologists throughout the UK.

For people currently under the care of the London Ataxia Centre, if you feel that your health is deteriorating with respect to your ataxia, you can contact the London Ataxia Centre between appointments using the contact details provided to you.

Contact details for referrals and general enquiries:

Professor Paola Giunti
The London Ataxia Centre
National Hospital for Neurology and Neurosurgery
Internal Box 12
Queen Square
London WC1N 3BG

Email: uclh.ataxia@nhs.net

Direct Line: 0203 4483100

Please note GPs should use the 'NHS E-referral' system for referring patients.