



## 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 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 service is led by consultant neurologists and is supported by a multidisciplinary team comprising of a physiotherapist, specialist nurse, an occupational therapist, and a speech and language therapist. There is also a team of medical researchers and a research trial co-ordinator who attend clinics.

### **Neurologist-led general ataxia clinic**

The neurologist-led general ataxia clinic, which run three times a week, supports the investigation and monitoring of ataxia, and where appropriate, genetic counselling. It is a specialised service 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 the newly established **interdisciplinary therapy clinic** (see below)
- 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
  - Neuro-ophthalmology

- Neuropsychology
- Neurological and spinal surgery
- Orthopaedics
- 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 and neurogenetic nurse. These nurses are available to discuss medical, social or financial queries.
- Establishment of an ataxia database, facilitating research.
- Close links with the Neurogenetics Unit which allows the development of new genetic tests.

### **Interdisciplinary therapy clinic**

The interdisciplinary therapy clinic comprises the lead neurologist specialising in ataxia, an occupational therapist, physiotherapist and speech and language therapist with particular expertise in adult neurological rehabilitation, and the clinical nurse specialist. The clinic runs fortnightly 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 telephone clinics**

Nurse led telephone 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 Specialist works within the multi-professional team and will ensure that any concerns are communicated to all necessary members.

### **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. They are therefore able to offer up-to-date information on the current state of research and participation in a number of 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. Prof Paola Giunti is the UK representative on the board of the network.

### **The centre is currently recruiting for a number of trials, including:**

- EFACTS – European Friedreich's Ataxia Consortium for Translational Studies

- ESMI: European Spinocerebellar Ataxia Type 3/Machado-Joseph Disease Initiative
- EUROSCA – European Integrated Project on the Spinocerebellar Ataxias
- Detecting retinal changes in autosomal recessive spastic ataxia of Charlevoix-Saguenay (ARSACS) and other ataxias using optical coherence tomography

**The centre is also taking part in lab based projects, including:**

- Investigating the role of oxygen levels in Friedreich's ataxia
- Understanding the role of CAG repeat on the phenotype exhibited in polyglutamine disease

More information about any of these studies, and details of how to take part in the studies which are currently recruiting studies can be found in the accompanying '**London Ataxia Centre – Research Projects**' leaflet.

**The Clinic team**

The clinic team is led by Prof Paola Giunti and supported by the following neurologists, Dr Mike Parkinson, Dr Hector Garcia and Dr Gilbert Thomas-Black. The clinic team also includes the ataxia nurse, Suzanne Booth ([suzanne.booth3@nhs.net](mailto:suzanne.booth3@nhs.net)), the research trial co-ordinator, Nita Solanky, and the neurogenetics nurse, Liz Redmond ([liz.redmond@nhs.net](mailto:liz.redmond@nhs.net)). The contact number for the team is 0203 448 3100.

After the ataxia clinic visit patients have the opportunity to talk to 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.

**Anyone interested in getting an appointment to attend the ataxia clinic should ask their doctor or neurologist for a referral. Referrals are accepted from GPs and neurologists throughout the UK.**

**Contact details for referrals:**

**Prof Paola Giunti**

National Hospital for Neurology and Neurosurgery

Queen Square

London WC1N 3BG

0203 448 3100

Please note GPs should use the 'choose and book' system for referring patients.