



## Ataxia UK accredited Specialist Ataxia Centres – Children's Ataxia Clinic at the London Ataxia Centre

The Paediatric Ataxia Clinic is the new service at the National Hospital for Neurology and Neurosurgery (NHNN) Ataxia Centre. The London Ataxia Centre at NHNN was launched by Professor Paola Giunti in 2005, and was accredited as the first centre of excellence by the patient organisation Ataxia UK. The Paediatric Ataxia Clinic brings a new service to the London Ataxia Centre, enabling children with ataxia to receive care at this centre of excellence.

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'.

### **Research focus**

The Paediatric Ataxia Clinic leads a large 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.

### **Education focus**

At the Paediatric Ataxia Clinic, their mission is to improve knowledge on the conditions seen and develop a new workforce to deliver the best care for children with ataxia in secondary and primary care. There are exciting opportunities to learn from experts and, perhaps more importantly, from patients.

### **Their vision**

While the team at the Paediatric Ataxia Clinic work and research towards finding cures for children with ataxia, they want to ensure that every child and adolescent with ataxia can maximise their physical, emotional, and social well-being.

The team at the Paediatric Ataxia Clinic are committed to providing a holistic care service for children and families who have or are at risk of ataxia, which includes preparing and supporting the transition towards adult services. Good practice in transitional care can improve ongoing engagement with services and can lead to positive health outcomes. For this reason, transition to adult services will be a focus of clinics for children aged 16-18.

Ataxia UK, 12 Broadbent Close, London N6 5JW

Office 020 7582 1444 Helpline 0800 995 6037 [office@ataxia.org.uk](mailto:office@ataxia.org.uk) [www.ataxia.org.uk](http://www.ataxia.org.uk)

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The children's clinic also benefits from streamlined referrals to other specialists, at the National Hospital or Great Ormond Street depending on the age of the patient, with expertise in managing ataxia related symptoms, for example cardiology for children with Friedreich's ataxia.

### **Research Collaborators**

European Paediatric Neurology Society (EPNS) - childhood ataxia and cerebellar group  
Ataxia Global Initiative

European Friedreich's Ataxia Consortium for Translational Studies (EFACTS)

100,000 Genomes project of Genomics England

European Reference Network for Rare Neurological Diseases (ERN-RND)

### **Local care**

It is essential to ensure that children referred to the Paediatric Ataxia Clinic are monitored and supported by a community paediatrician, a local paediatric neuro-disability specialist or a paediatric neurologist, and other health care professionals between visits to the specialised centre.

### **The Clinic Team**

Professor Paola Giunti – adult neurologist, leading the London Ataxia Centre

Dr Shpresa Pula – Consultant in Paediatric Neurology

Ms Katarina Manso - specialized ataxia nurse

Initially there will be Specialist Children's Ataxia Clinic three times a year. The centre will see children and young people between 8 and 18 years of age. Support both during and between clinic visits will be available via the ataxia nurse. The clinic team can be contacted at [uclh.ataxia@nhs.net](mailto:uclh.ataxia@nhs.net). Clinics will take place at University College London Hospital (Elizabeth Garrett Anderson Hospital).

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 paediatric ataxia clinic should ask their doctor or neurologist for a referral. Referrals are accepted from GPs and neurologists throughout the UK. Referrals will be selected on a case-by-case basis. Initially, priority will be given to children with a diagnosis of a genetic ataxia. The age range for referrals is 8-18.**

### **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.

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