

# Ataxia UK Specialist Ataxia Clinic

at the National Hospital for  
Neurology and Neurosurgery, London

**Ataxia UK accredited Ataxia Centres are Centres of Excellence**, where people with ataxia should receive the best possible quality of care and a co-ordinated service combining diagnosis, treatment, support and research. You are guaranteed to be seen by a neurologist with expertise in the ataxias. An accredited Centre must also comply with other criteria. (Contact Ataxia UK for further information.)

The Centres have been set up in direct response to needs identified by people affected by ataxia, as well as clinicians with expertise in the condition.



*Dr Paola Giunti with one of her patients at the London Ataxia Centre*

The Centre at the National Hospital in London is the first Accredited Centre in England.



## The London Ataxia Clinic

The clinic is held once a week. 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:

- Longer 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. (Patients are able to see a physiotherapist, speech and language therapist and an occupational therapist in one clinic.)
- Streamlined referrals to other specialists already interested in the ataxias, as appropriate. Named specialists in the following disciplines have already agreed to see ataxia patients:
  - cardiology
  - neuropsychiatry
  - neurophysiology
  - neuro-ophthalmology
  - neuropsychology
  - neurological and spinal surgery
  - orthopaedics

Continued overleaf...

- Support both during and between clinic visits via the neurogenetic nurse. This nurse is available to discuss medical, social or financial queries
- Close links with primary, community and secondary care services for shared care and education on the ataxias
- Establishment of an ataxia database, facilitating research
- Validation of new genetic tests as they emerge

#### **Involvement in Research:**

The team at the London Ataxia Centre is also involved in various research projects. Patients who are interested may therefore have the opportunity to take part in research.

- a genetic screening study for determining a diagnosis of SCA11 (for which the gene was recently found by this team)
- verification of the value of validated ataxia rating scales for future use in therapeutic trials

#### **Current projects include:**

- an EC funded multi-centre natural history study

Also, a clinical trial for Friedreich's ataxia started in 2008.

#### **The Clinic Team:**

The clinic team includes Dr Paola Giunti and a neurogenetics nurse, Liz Redmond on 0845 155 5000 ext 84487

After the 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:**

##### **Dr Giunti**

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