



## Ataxia UK accredited Specialist Ataxia Centre for adults and children – Oxford

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 people 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 Oxford Ataxia Centre**

The Oxford Ataxia Centre is at the John Radcliffe Hospital. It offers a specialised service for all patients (adults and children) with a suspected or confirmed ataxia. The service is provided by a multidisciplinary team including adult neurologists, clinical geneticists, and a paediatric neurologist.

The Oxford Ataxia Centre provides:

- Long appointments – 60 minutes for new patients, 45 minutes for follow-up
- Continuity of care – patients see the same Clinician
- Multidisciplinary Team including a Consultant Clinical Geneticist
- Support between clinic visits by the clinical team
- 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
- Referral to physiotherapy, speech and language therapy and occupational therapy
- Streamlined referrals to other specialists already interested in the ataxias, as appropriate. Named specialists in the following disciplines see ataxia patients for the clinic:
  - Cardiology
  - Neurophysiology
  - Neuro-ophthalmology
  - Orthopaedics

## **Involvement in research**

The team at the Oxford Ataxia Centre is involved in various research projects. Patients who are interested may therefore have the opportunity to take part in research. The aim of many of these projects is to improve assessments of patients for future clinical trials.

Current projects include:

- Identification of a large set of patients with STUB1 related ataxia.
- Identification of patients with likely genetic ataxia without a genetic diagnosis.
- Quantitative motor assessment and development of novel outcome measures in patients with ataxia (collaboration with Professor Helen Dawes and team, Exeter University)

## **The Clinic team**

### **Clinical Geneticist**

Prof Andrea Nemeth

### **Adult Neurologists**

Prof George Tofaris

Dr Carlo Rinaldi

### **Paediatric Neurologist**

Dr Martin Smith

**Anyone interested in getting an appointment to attend the Ataxia centre should ask their doctor or neurologist for a referral. Referrals are accepted from GPs and neurologists throughout the UK. All patients are seen jointly.**

## **Contact details for referrals:**

### **Prof George Tofaris/A/Prof Carlo Rinaldi (Adult Neurologists)**

Department of Neurology

John Radcliffe Hospital

Oxford

OX3 9DU

Secretary to Prof Tofaris: 01865 231295

### **Prof Andrea Nemeth (Clinical Geneticist sees adults and children)**

Department of Clinical Genetics

Churchill Hospital

Oxford

OX3 7LJ

Secretary to Prof Nemeth: 01865 220624, Option 5

### **Dr Martin Smith (Paediatric Neurologist)**

Department of Paediatric Neurology

Oxford Childrens Hospital

OX3 9DU

Secretary to Dr Smith: 01865 221579