



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
- Virtual follow up appointments are available if required
- Continuity of care – patients see the same clinician or a registrar within their team
- 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.

Current projects include:

- Oxford Ataxia Centre is a site for the BRAVE global Phase 3 paediatric trial evaluating the effects and safety of omaveloxolone for the treatment of Friedreich's Ataxia in children aged 2-15.
- Development of organoid systems to model Friedreich's ataxia (Prof Rinaldi, Prof Becker, Associate Prof Toepfer)
- Reversing *FXN* locus Silencing via Precision Epigenetic Therapy (Prof Rinaldi, Prof Becker, Associate Prof Toepfer)
- Using artificial intelligence (AI) exercise gaming fused with motion capture to create a novel digital clinical outcome assessment in Friedreich's Ataxia (collaboration with Prof Helen Dawes, University of Exeter, and researchers in Sao Paolo).
- SCA44 natural history study (collaboration with Prof Helen Dawes)

The Clinic team

Clinical Geneticist

Prof Andrea Nemeth

Adult Neurologists

Prof George Tofaris

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

Contact details for referrals:

Prof George Tofaris/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

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