

## ATAXIA UK ACCREDITED CENTRES



Ataxia UK Accredited Centres are ataxia centres of excellence. These are based in NHS Trusts in the UK and are headed by a clinician with expertise and interest in ataxia. In order to become an Ataxia UK Accredited Centre a number of criteria need to be met (see below). These have been devised following consultation with people with ataxia and their carers and with neurologists. The Centres aim to provide good diagnostic and follow-up services, referrals to relevant professionals and good communication between professionals and patients. There is a willingness to collaborate between Centres in order to ensure the best services to patients and in order to help in research efforts.

### CRITERIA FOR ATAXIA UK ACCREDITED CENTRES

1. Involvement of clinician(s) with interest/expertise in ataxia over a number of years and seeing on average at least 8 ataxia patients per month. In this context 'ataxia patients' are defined as people with ataxia as their dominant clinical syndrome.
2. Involvement of clinician(s) with a track record of research on the ataxias or who can provide evidence that they keep updated on recent developments in ataxia research
3. Access to **all** relevant available genetic and non-genetic diagnostic tests  
It is important that people attending any of the Centres have access to the most up-to-date diagnostic tests and that there is equality in the availability of tests in all centres. In some cases, eg for rare genetic tests, it may be appropriate for all tests to be carried out through one Centre.  
Testing should include all relevant imaging, neurophysiological, biochemical, immunological and genetic tests.
4. Follow-up offered (at least once a year) with continuity of care (ie: see same neurologist at least 3 out of 4 visits).
5. Good, supportive handling of diagnosis and other sensitive information (monitored by feedback from people attending the centre and/or carers).
6. Evidence of good referral service to support services to include physiotherapists, OT's, speech therapists and Ataxia UK.
7. Direct referral to other specialist clinical services (e.g. cardiologists, orthopaedists, psychiatrists, ophthalmologists etc.) with fast track potential for relevant cases.
8. Evidence of good communication with primary care
9. Evidence of links with and support of local paediatric neurologists

10. Evidence of a system for providing both medical information and support /advice for people with ataxia and carers between clinic visits.
11. Willingness to input patient information to a local database
12. Willingness to collaborate with other Ataxia Centres in research (e.g. for recruitment to trials, validation of novel genes or other research projects).
13. Preparedness to accept GP referral from non-local patients.
14. Evidence that the relevant NHS Trust supports the development of an Ataxia Centre.
15. Agreement to implement an annual monitoring system based on patient feedback.
16. Willingness to attend annual meeting of ataxia centres (for problem solving, best practice and research discussions).

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