

## **Research studies currently recruiting participants with Gluten ataxia:**



**Improving diagnosis and management of gluten ataxia Study** - Ataxia UK, Coeliac UK, the Sheffield Hospital Charity and the Greaves and Withey Foundation awarded funding to Professor Marios Hadjivassiliou, at the Sheffield Ataxia Centre and colleagues, to help improve the diagnosis and management of gluten ataxia.

Click [here](#) to find out how to take part.

Read here an article from the Ataxia UK magazine on the study:

### **Ataxia UK funds project to improve the diagnosis and management of gluten ataxia**

Ataxia UK, Coeliac UK, the Sheffield Hospital Charity and the Greaves and Withey Foundation have awarded funding to Professor Marios Hadjivassiliou, Director of the Sheffield Ataxia Centre (right), Sheffield Teaching Hospitals NHS Trust, and colleagues, to help improve the diagnosis and management of gluten ataxia.

Their aim is to develop a clear diagnostic pathway that can be used by neurologists so that more people with gluten ataxia can be diagnosed earlier. This is a collaborative project involving other Neurology Centres with an interest in ataxia across the UK, including the London and Oxford Ataxia Centres.

Gluten ataxia is caused by a sensitivity to gluten, which is found in wheat, barley and rye products. This sensitivity means that when people with gluten ataxia eat gluten, the body's immune system produces antibodies. These antibodies can then attack the balance centre of the brain and cause the symptoms of ataxia. Gluten ataxia can be treated by a strict gluten-free diet, which has been shown to stop the progression and potentially improve ataxia symptoms if started early enough. Therefore, early diagnosis of gluten ataxia is extremely important.

While some people with gluten ataxia will also have coeliac disease (inflammation of the small bowel causing abdominal pain, altered bowel habit, bloating and malabsorption), the majority do not, and will test negative in the widely available blood tests used to diagnose coeliac disease. Previous research by Professor Hadjivassiliou and colleagues showed that people with gluten ataxia have antibodies called tissue transglutaminase 6 (tTG6) and antigliadin antibodies present in their blood, and these can be tested in addition to the widely available coeliac blood tests to diagnose gluten ataxia. This testing is currently available in Sheffield under the NHS but not in other laboratories in the UK.

In this study, the Sheffield Ataxia Centre will work with other neurologists throughout the UK who have clinics for people with ataxia (London, Oxford, Manchester, Romford). People who have had tests to rule out other types of ataxia and who still do not have a diagnosis of the cause of their ataxia will be referred to the Sheffield Ataxia Centre to be tested for gluten ataxia. This will include tTG6 and antigliadin

antibody tests and, if positive for these antibodies, a gut biopsy. Those diagnosed with gluten ataxia will be advised to follow a strict gluten-free diet. They will then be followed up after one year to assess the impact of the gluten-free diet. If you are interested in being involved in the project (and you are attending one of the centres involved), speak to your neurologist about taking part.

Read here a previous Ataxia UK magazine article on the test for Gluten ataxia:

## **Gluten ataxia research – New diagnostic test**

Neurologist Prof Marios Hadjivassiliou, who runs the Sheffield Specialist Ataxia Centre and has expertise in gluten ataxia, has published results in the journal *Neurology*\* describing a new test that will help improve diagnosis of gluten ataxia.

Patients with cerebellar ataxia of unknown cause are currently tested for gluten sensitivity using a blood test for antibodies called gliadins. If they test positive they are given a diagnosis of gluten ataxia and are recommended to go on a gluten-free diet. Diagnosis is very important as this is one of the few treatable ataxias if diagnosed early enough. In this new study, the team in Sheffield and collaborators in Cardiff hypothesised that a different antibody against a brain enzyme called transglutaminase 6 (TG6) could be used as a diagnostic test for gluten ataxia. They found that a high proportion of those diagnosed with gluten ataxia in the traditional way also tested positive for TG6 antibodies (and, as expected, the healthy controls tested negatively). In addition, a Finnish group showed that after one year on a gluten-free diet the TG6 antibodies decreased in 11 out of 12 patients. These results show that the TG6 antibody test is a sensitive test for diagnosing gluten ataxia.

The researchers in Sheffield then also tested 65 patients with cerebellar ataxia of unknown cause who were negative for the gliadin antibodies, and thus would have had a negative diagnosis for gluten ataxia. They found that 21 (i.e 32%) of these were positive for TG6. This suggests that the TG6 test might be more sensitive than the anti-gliadin antibody test, and that the prevalence of people with gluten ataxia is higher than previously thought.

If anyone with idiopathic cerebellar ataxia is interested in being tested for gluten ataxia they should ask for a referral to the Sheffield Specialist Ataxia Centre (see Ataxia UK's leaflet) or could ask their neurologist to contact Prof Marios Hadjivassiliou at the Sheffield Teaching Hospitals NHS Foundation Trust. He is currently doing these tests on a research basis although there are plans to introduce them as diagnostic tests within the NHS.

\*Reference:

Hadjivassiliou *et al.* *Neurology* 2013, May 7;80(19):1740-5.

**For more support or information please contact:**

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We have a number of other publications on the ataxias available free of charge. In addition we publish a quarterly magazine called The Ataxia Magazine containing articles on research, living with ataxia and other relevant information. Our website also contains news of research projects.

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