

Car Parking / Refreshments

There is car parking on the hospital site with limited access to disability spaces. There is a coffee shop on site and a hospital dining room also.

Follow-up

A letter for your next appointment will be sent to you approximately six weeks prior to your follow-up appointment.

Contact the team

If you need to contact a member of the Ataxia Clinic Team please contact the department secretary on 01 414 2090 or email neurologyopd@tuh.ie Please make a note of any questions you would like to ask:



http://www.orpha.net/national/IE-EN/index/homepage/



PATIENT INFORMATION BOOKLET

Ataxia

The National Ataxia Clinic

What is Ataxia



Ataxia is a term used to describe problems with balance and coordination. There are many causes of ataxia and this condition affects people in different ways.

National Ataxia Clinic at Tallaght University Hospital

The National Ataxia Clinic in Tallaght University Hospital is the only designated centre of expertise for the diagnosis and management of ataxia and Hereditary Spastic Paraplegia (HSP) in the Republic of Ireland. In order to ensure continuity of care within community services, a referral to allied health professional i.e. speech, occupational or physiotherapy, can be arranged

The clinic provides a highly specialised service for patients with suspected or confirmed inherited (genetic) or acquired causes of Ataxia & HSP as many forms of them are very rare, diagnosis can be difficult. It may be facilitated by specialists at the National Ataxia Centre. There is a monthly multidisciplinary Ataxia & HSP clinic co-ordinated by Consultant Neurologists, Prof Sinéad Murphy, Prof Richard Walsh, Dr Petya Bogdanova-Mihaylova in conjunction with Specialist Neurology Registrars and visiting Neurology Fellows.

In addition, there is a Combined Ataxia Clinic which runs four times a year. Dr Deirdre Ward, a Cardiologist with a special interest in inherited cardiac disorders will assess patients such as those with Friedreich's Ataxia. A cardiac echo can be arranged on the same day thus saving patients' additional hospital visits.

Involvement in Research

The clinic is a member of the European Reference Network (ERN) for Rare Neurological Diseases (**www.ernrnd.eu**). The aims of the ERN is to share, care and cure rare disease. People at the Ataxia & HSP clinics, now, have the opportunity to enrol in the European patient registry for rare diseases.

This is an opportunity for patients with rare neurological diseases to be brought together to obtain information on the frequency, course of the diseases and to be ready for clinical trials. In the register, data is only collected in a coded form and without any identifying information.

For those with Friedreich's Ataxia, they will be invited to enrol in the International Friedreich's Ataxia Registry - UNIFAI (for short) See <u>www.clinicaltrials.gov</u>) or contact <u>mary.kearney02@tuh.ie</u>

What to bring on the day of your appointment?

Bring someone with you if possible.

 It can be helpful to bring a family member or friend with you. The day of your appointment can be a long day so it helps to have someone to chat to as you wait to see the doctor.

Bring a list.

- A full list of your medications including the amounts that you take. Please remember to include any vitamins and supplements you are taking.
- Please also bring any other hospital, GP letters or test results since your last appointment you may have that are relevant
- Bring a list of your current most troublesome symptoms and questions with the most important ones at the top of the list.

Who will I see in clinic?

- A doctor with expertise in ataxia.
- You may have a blood test, x-ray or an eye test.