

National Ataxia Clinic

The National Ataxia Clinic in Tallaght University Hospital is the only designated centre of expertise for the diagnosis and management of Ataxia in the Republic of Ireland. It provides a highly specialised service for patients with suspected or confirmed inherited (genetic) or acquired causes of ataxia. As many forms of ataxia are very rare it is vital that accurate diagnosis is facilitated by specialists with expertise in the diagnosis and management of rare forms of ataxia.

In our Combined Ataxia Clinic which runs four times a year, Dr Deirdre Ward, a Cardiologist with a special interest in inherited cardiac disorders, assesses patients with Friedreich's Ataxia with cardiac echo on the same day saving patients additional hospital visits.

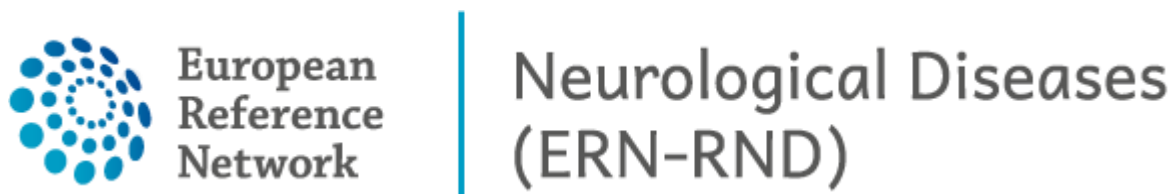
TUH is the lead Irish site for the European Reference Network for Rare Neurological Diseases (ERN-RND). The team at the National Ataxia Clinic at Tallaght University Hospital is also involved in various research projects.

Research Studies

EFACTS (European Friedreich's Ataxia Consortium for Translational Studies) currently in the process of transitioning into UNIFAI (Friedreich Ataxia Global Clinical Consortium UNIFIED Natural History Study).

POL3RA Multi National Natural History Study

Pregnancy and Friedreich's Ataxia



Objectives of ERN-RND

- To significantly increase the overall percentage of RND patients with a final diagnosis
- To improve and harmonise care of RND patients across the EU
- To develop, share and implement care pathways and guidelines for all RND groups represented in ERN-RND
- To develop a comprehensive and data based European RND cohort to better understand these conditions and thus improve their management and help developing and testing treatments

EFACTS (European Friedreich's Ataxia Consortium for Translational Studies)



EFACTS (the European Friedreich's Ataxia Consortium for Translational Studies) assembles a body of expertise to adopt a translational research strategy for the rare autosomal recessive neurological disease, Friedreich's ataxia (FRDA)

Objectives of EFACTS

- **Comprehensively populate a European FRDA database, linked to a bio bank**
- **Define a panel of clinical assessment tools**
- **Develop new cellular and animal models for the study of FRDA**
- **Identify FRDA biomarkers**
- **Identify genetic modifiers of FRDA**
- **Develop therapeutics for FRDA**

UNIFAI (Friedreich Ataxia Global Clinical Consortium UNIFIED Natural History Study)



UNIFAI Mission Statement:

to marshal and focus the resources and relationships needed to cure FRDA by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to curing FRDA and related diseases.

POL3RA Multi National Natural History Study



TUH is going to participate in the TreatPOLR3A Natural History Study. The main site for this study is Heidelberg University Hospital & Heidelberg Faculty of Medicine which is a member of the ERN-RND.

This natural history study is intended as a run-in natural history study for patients who may enter a clinical trial later.

Pregnancy and Friedreich's Ataxia

TUH is the lead site in this ERN-RND project investigating the impact of Friedreich's Ataxia (FRDA) on pregnancy and the effect of pregnancy on cardiac and neurological function in women with FRDA. This information will provide us with the evidence to further compile recommendations to support pregnancy in women with FRDA.