

16 April 2025

## **Friedreich Ataxia Services**

**I have a Freedom of Information request regarding Friedreich Ataxia services in your organisation. Could you please help by answering the following questions?**

Belfast Trust's Neurology service has a Movement Disorders Clinic and Ataxia patients are seen within it.

The Neurology service do not have any systems to answer the remaining questions and the time that would be required to manually ascertain this information would fall within the exemption criteria for FOI requests i.e. more than 18 hours.

Belfast Trust considers that the cost of retrieving the information would be above the 'Appropriate Limit', as defined by the Freedom of Information Act under Section 12. Section 12 of the Freedom of Information Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit. The limit has been specified as £450 for public authorities such as Belfast Trust. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

**1. Of all patients diagnosed with Hereditary Ataxia (ICD-10 Code G11), how many have a specific diagnosis of Friedreich Ataxia?**

**1a. How many Friedreich Ataxia patients have been diagnosed in the last 12 months?**

**1b. How many Friedreich Ataxia patients have had an appointment in the last 12 months in the following departments?**

- **Cardiology**
- **Neurology**
- **Neuromuscular**
- **Specialist movement disorders**
- **Any other department**

**1c. How many Friedreich Ataxia patients fall within the following age groups?**

- **0-13**
- **14-15**
- **16-40**
- **40+**

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- 1d. How many Friedreich Ataxia patients have you discharged in the last 12 months?**
- 1e. How many Friedreich Ataxia patients have you referred to another specialist centre?**
- 2. Does your centre have a specialist movement disorders clinic?**
  - If so, how many patients with a diagnosis of Fredreich Ataxia have visited the clinic in the last 12 months?**
- 3. Does your centre have a specialist Ataxia Clinic, as part of the specialist movement disorders clinic?**
  - If so, how many patients with a diagnosis of Fredreich Ataxia have visited the clinic in the last 12 months?**