

FOI 2983

1st April 2025

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

I have a freedom of information request regarding Friedreich Ataxia services in your organisation, could you please help by answering the following questions:

Q1. Of all patients diagnosed with Hereditary Ataxia (ICD-10 Code G11), how many have a specific diagnosis of Friedreich Ataxia?

Response:

This is a rare disease, and we are not aware of any paediatric patients in the Southern Trust.

Q1a. How many Friedreich Ataxia patients have been diagnosed in the last 12 months?

Response:

No paediatric patients have been diagnosed in the last 12 months.

Please see attachment for response from adult acute services, it has not been possible to identify when patients were diagnosed but can give patient day care or had a finished consultant episode.

Usually, the diagnosis is made by Neurology and Genetics so would recommend that these questions are directed to tertiary care Royal Belfast Hospital for Sick Children Belfast Health and Social Care Trust.

Q1b. 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**

Response:

No paediatric patients have been diagnosed in the last 12 months.

Please see attachment for response from adult acute services.

Q1c. How many Friedreich Ataxia patients fall within the following age groups?

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

· 40+

Response:

No paediatric patients have been diagnosed in the last 12 months.
Please see attachment for response from adult acute services.

Q1d. How many Friedreich Ataxia patients have you discharged in the last 12 months?

Response:

See response to 1a and 1b

Q1e. How many Friedreich Ataxia patients have you referred to another specialist centre?

Response:

See response to 1a and 1b

Q2. Does your centre have a specialist movement disorders clinic?

Response:

See response to 1a and 1b

· **If so, how many patients with a diagnosis of Fredreich Ataxia have visited the clinic in the last 12 months?**

Response:

Not applicable

Q3. Does your centre have a specialist Ataxia Clinic, as part of the specialist movement disorders clinic?

Response:

See response to 1a and 1b

· **If so, how many patients with a diagnosis of Fredreich Ataxia have visited the clinic in the last 12 months?**

Response:

Not applicable.

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