

Date 25/04/2025
 Your Ref
 Our Ref 9826

Enquiries to Richard Mutch
 Extension 35687
 Direct Line 0131 465 5687
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Dear

FREEDOM OF INFORMATION – HEREDITARY ATAXIA

I write in response to your request for information in relation to Hereditary Ataxia.

Question:

1. Of all patients diagnosed with Hereditary Ataxia (ICD-10 Code G11), how many have a specific diagnosis of Friedreich Ataxia?
 - a) Q1a. How many Friedreich Ataxia patients have been diagnosed in the last 12 months?
 - b) 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
 - c) How many Friedreich Ataxia patients fall within the following age groups?
 - 0-13
 - 14-15
 - 16-40
 - 40+
 - d) How many Friedreich Ataxia patients have you discharged in the last 12 months?

Answer:

| | |
|----|---|
| a. | We cannot differentiate between clinical diagnosis or a molecular confirmation of a clinical diagnosis, but we tested in the region of 123 sample last year for the ataxia expansion panel. Of that number, 5<had FRDA. |
| b. | We also received 27 requests for FRDA alone- of that number five or fewer were affected, however five or fewer of those were requests for confirmatory testing of the result generated by another laboratory. |
| c. | 0-13 - 5< 14-15 - 5< |

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Chair Professor John Connaghan CBE
 Chief Executive Professor Caroline Hiscox
 Lothian NHS Board is the common name of Lothian Health Board





| | | |
|----|-------------------|------------|
| | 16-40 - 5< 40+ | |
| d. | Diagnosis | Discharges |
| | G11 | 23 |
| | G11.1 | 5< |

Question:

2. Does your Health Board 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?

Answer:

Yes. Patient numbers are not held in a centrally extractable format. Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

Question:

3. Does your Health Board 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?

Answer:

No

Question:

4. As the lead centre in Scotland responsible for Friedrich Ataxia Testing (FRDA) as part of the Scottish Strategic Network for Genomic Medicine, how many samples have you received for Friedrich Ataxia testing in the last 12 months?

Answer:

Specifically for FRDA alone - we received 27 requests.

To protect the identity of the individuals involved any figure of 5 or less has not been shown in this response. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018).



I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhslothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive