

Date 13/06/2025
Your Ref
Our Ref 10111

Enquiries to Richard Mutch
Extension 35687
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loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION - SPINAL MUSCULAR ATROPHY

I write in response to your request for information in relation to Spinal Muscular Atrophy.

Question:

- How many patients have a current diagnosis for Spinal Muscular Atrophy (ICD-10 Code G12.0, G12.1, G12.8 and G12.9) at your trust?
- How many patients have been treated in the last 4 months (January to April 2025) with the following products:
 - Evrysdi (Risdiplam) - total patients
 - Spinraza (Nusinersen) - total patients
 - Zolgensma (Onasemnogene) - total patients
 - Evrysdi (Risdiplam) – new* patients
 - Spinraza (Nusinersen) – new* patients
 - Zolgensma (Onasemnogene) – new* patients

*new patients are defined as patients who were not treated with any of Spinraza (Nusinersen), Evrysdi (Risdiplam) or Zolgensma (Onasemnogene) in the previous 4-month period (September to December 2024).

Answer:

Medication	Patient Count
Evrysdi (Risdiplam) - Total Patients	7
Spinraza (Nusinersen) - Total Patients	Information Unavailable
Zolgensma (Onasemnogene) - Total Patients	0
Evrysdi (Risdiplam) - New Patients	5<
Spinraza (Nusinersen) - New Patients	Information Unavailable
Zolgensma (Onasemnogene) - New Patients	0

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

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

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the table above. 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).

Question:

3. Of the total patients treated in the last 4 months (January to April 2025) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (September to December 2024).
4. Of the total patients treated in the last 4 months (January to April 2025) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (September to December 2024).
5. Of the total patients treated in the last 4 months (January to April 2025) with Spinraza (Nusinersen) please provide the number of patients that were treated with Evrysdi (Risdiplam) in the previous 4 months (September to December 2024).

Answer:

We are unable to provide an answer as Zolgensma (Onasemnogene) is not available in our system, and patient-specific issues related to Spinraza (Nusinersen) cannot be identified. 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.

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.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive