

Freedom of Information request 33-23

Request

1. 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?
2. How many patients have been treated in the last 4 months (September to December 2022) 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 (May to August 2022).

3. Of the total patients treated in the last 4 months (September to December 2022) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).
4. Of the total patients treated in the last 4 months (September to December 2022) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).
5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2022)?

Response

1. There are currently no NHS Borders patients who are receiving treatment for Spinal Muscular Atrophy.
2. There have been no NHS Borders patients treated with Evrysdi (Risdiplam), Spinraza (Nusinersen) or Zolgensma (Onasemnogene).
3. N/A
4. N/A
5. There have been no NHS Borders patients treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2022).

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **33-23** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.