

6 October 2025

**Our Ref:** FOI 1397

Dear

**Freedom of Information Act 2000  
Information in Relation to Spinal Muscular Atrophy**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above, which you requested on 9 September 2025.

A response to the questions you have raised has been provided by the Surgery, Elective Care, Maternity and Paediatrics Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital ([informationgovernance@setrust.hscni.net](mailto:informationgovernance@setrust.hscni.net)) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

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**Olivia Robinson**  
**Information Governance Officer**

**Q1. 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?**

A1. The Trust does not capture the diagnosis broken down by Spinal Muscular Atrophy.

However, the Trust can provide the total number of inpatient discharges from Ulster, Lagan Valley, Downe and Ards Hospitals who had Spinal Muscular Atrophy during the last calendar year for which coding is complete.

There has been 28 unique inpatients discharged from 1 January 2024 to 31 December 2024 where a Spinal Muscular Atrophy diagnosis has been recorded as part of their stay. Please note that if a patient had a diagnosis but was not discharged from one of the Trust's inpatient settings during that timeframe then they would not be included.

**Q2. How many patients have been treated in the last 4 months (May to August 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 (January to April 2025).**

**Q3. Of the total patients treated in the last 4 months (May to August 2025) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (January to April 2025).**

**Q4. Of the total patients treated in the last 4 months (May to August 2025) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (January to April 2025).**

**Q5. Of the total patients treated in the last 4 months (May to August 2025) with Spinraza (Nusinersen) please provide the number of patients that were treated with Evrysdi (Risdiplam) in the previous 4 months (January to April 2025).**

A2-5. The Trust does not hold this information. However, The Belfast Health and Social Care Trust (Belfast Trust) may be able to help with this request. You can contact the Belfast Trust at [publicliaison@belfasttrust.hscni.net](mailto:publicliaison@belfasttrust.hscni.net).