

27th May 2025

FOI Request On Spinal Muscular Atrophy

Question 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?

Question 2. 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).**

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).

Question 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).

Question 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).

We cannot provide an answer to this request as Belfast Trust no longer provide this service.

It would fall under the Neuro Muscular Service, which is now based in South Eastern Health Trust. Please see link below for contact details.

<https://setrust.hscni.net>