

Freedom of Information Request: Our Reference CTMUHB_32_23

You asked:

We have a freedom of information request related to the diagnosis and treatment of Spinal Muscular Atrophy. Your answers to the following questions would be greatly appreciated.

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)?

Our response:

The Health does not hold the information requested.

Cwm Taf Morgannwg University Health Board commission Neurological Services from Cardiff & Vale (C&V) and Swansea Bay (SB) University Health Boards (UHB) with Consultants providing outreach services to Cwm Taf Morgannwg (CTM) patients. Support is also provided within C&V and SB UHB's for patients with more complex needs/those who require specialist inpatient care.

Therefore, you may wish to redirect your request directly to:
Cardiff and Vale University Health Board - CAV.FOI.Requests@wales.nhs.uk
Swansea Bay University Health Board - FOIA.Requests@wales.nhs.uk