



**GIG**  
CYMRU  
**NHS**  
WALES

Bwrdd Iechyd Prifysgol  
Bae Abertawe  
Swansea Bay University  
Health Board

Cadeirydd/Chair: **Emma Woollett**  
Prif Weithredwr/Chief Executive: **Mark Hackett**

**gofalu am ein gilydd, cydweithio, gwella bob amser**  
**caring for each other, working together, always improving**

Rydym yn croesawu gohebiaeth yn y Gymraeg neu'r Saesneg. Atebir gohebiaeth Gymraeg yn y Gymraeg, ac ni fydd hyn yn arwain at oedi. We welcome correspondence in Welsh or English. Welsh language correspondence will be replied to in Welsh, and this will not lead to a delay.

## **Cais Rhyddid Gwybodaeth / Freedom of Information request** **Ein Cyf / Our Ref: 23-A-039**

### **You asked:**

#### **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 Health Board?**

As at 3<sup>rd</sup> February 2023, there are 6 patients (combination of adult and child) with a diagnosis of Spinal Muscular Atrophy under SBUHB.

#### **2. How many Spinal Muscular Atrophy patients have been treated in the last 4 months (September to December 2022) with the following products:**

- **Evrysdi (Risdiplam)** - <5 total patients
- **Spinraza (Nusinersen)** – 0 total patients
- **Zolgensma (Onasemnogene)** – 0 total patients
- **Evrysdi (Risdiplam)** – 0 new\* patients
- **Spinraza (Nusinersen)** - 0 new\* patients
- **Zolgensma (Onasemnogene)** – 0 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 Spinal Muscular Atrophy 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).**

0 patients

#### **4. Of the total Spinal Muscular Atrophy patients treated in the last 4 months (September to December 2022) with Zolgensma (Onasemnogene), please**



Pencadlys BIP Bae Abertawe, Un Porthfa Talbot, Port Talbot, SA12 7BR / Swansea Bay UHB Headquarters, One Talbot Gateway, Port Talbot, SA12 7BR

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Swansea Bay University Health Board is the operational name of Swansea Bay University Local Health Board

**provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).**

0 patients

**5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2022?)**

0 patients

Where fewer than 5 has been indicated we are unable to provide you with the exact number of patients as due to the low numbers, there is a potential risk of identifying individuals if this was disclosed. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.

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