

Date: Friday, 20th January 2023  
Our Ref: MB/CM FOI 5541

Sid Watkins Building  
Lower Lane  
Fazakerley  
Liverpool L9 7BB  
Tel: 01515253611  
Fax: 01515295500  
Direct Line: 01515563038

**Re: Freedom of Information Request FOI 5541**

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 17th January 2023.

Your request was as follows:

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?

[The Walton Centre NHS Foundation currently has 34 patients with a diagnosis of Spinal Muscular Atrophy.](#)

Question 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).

[Evrysdi \(Risdiplam\) - total patients - 6](#)

[Spinraza \(Nusinersen\) - total patients - zero](#)

[Zolgensma \(Onasemnogene\) - total patients - zero](#)

[Evrysdi \(Risdiplam\) - new\\* patients - 1](#)

[Spinraza \(Nusinersen\) - new\\* patients - zero](#)

[Zolgensma \(Onasemnogene\) - new\\* patients - zero](#)

Question 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).

Zero.

Question 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).

Zero.

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

Zero.

Please see our response above in [blue](#).

#### **Re-Use of Public Sector Information**

All information supplied by the Trust in answering a request for information (RFI) under the Freedom of Information Act 2000 will be subject to the terms of the Re-use of Public Sector Information Regulations 2005, Statutory Instrument 2005 No. 1515 which came into effect on 1st July 2005.

Under the terms of the Regulations, the Trust will licence the re-use of any or all information supplied if being used in a form and for the purpose other than which it was originally supplied. This license for re-use will be in line with the requirements of the Regulations and the licensing terms and fees as laid down by the Office of Public Sector Information (OPSI). Most licenses will be free; however the Trust reserves the right, in certain circumstances, to charge a fee for the re-use of some information which it deems to be of commercial value.

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If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to the Freedom of Information Office at the address above.

**Please remember to quote the reference number, FOI 5541 in any future communications.**

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Yours sincerely

*Mike Burns*

**Mr. Mike Burns, Executive Lead for Freedom of Information**