

FOI REF: 23/045

1st March 2023

Eastbourne District General Hospital
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Eastbourne
East Sussex
BN21 2UD

Tel: 0300 131 4500
Website: www.esht.nhs.uk

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

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?**

Clarification was sought with regard to your definition of the number of patients that have a current diagnosis for Spinal Muscular Atrophy, i.e. do you mean admissions with a diagnosis of Spinal Muscular Atrophy and if so over what period and with the diagnosis in any or primary position and confirmation was received as follows:

We require current inpatient and outpatients records.

We do not hold this information for Outpatients as diagnosis codes do not drill down to Outpatients.

East Sussex Healthcare NHS Trust has had 2 patients admitted within 1st January 2022 and 31st December 2022, neither of whom has the above condition in a primary position.

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).**

East Sussex Healthcare NHS Trust do not hold these drugs within its Pharmacy Department. They are Specialist Drugs, and we are not a Specialist Centre.

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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).**

Not applicable.

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).**

Not applicable.

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

Not applicable.

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Linda Thornhill (Mrs)
Corporate Governance Manager
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