

Title: Spinal Muscular Atrophy

Reference Number: RDF1219-23

Date of Response: 26/01/23

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

*Dear Royal Devon University Healthcare NHS Foundation Trust,*

*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?*

Answer: 8.

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

<b>Product</b>	<b>Patients</b>	<b>Trust Total</b>
<i>Evrysdi (Risdiplam)</i>	<i>total patients</i>	Nil
<i>Spinraza (Nusinersen)</i>	<i>total patients</i>	Nil
<i>Zolgensma (Onasemnogene)</i>	<i>total patients</i>	Nil
<i>Evrysdi (Risdiplam)</i>	<i>new* patients</i>	Nil
<i>Spinraza (Nusinersen)</i>	<i>new* patients</i>	Nil
<i>Zolgensma (Onasemnogene)</i>	<i>new* patients</i>	Nil

*\*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).*

Answer: Please see the table above.

- 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).*

Answer: Nil.

- 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).*

Answer: Nil.

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

Answer: Nil.