

I would be grateful if you provided me with details with respect to the following: under the Freedom of Information Act.

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.

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?

There were 32 patients, admitted as an inpatient or a daycase to a Health Board hospital in 2022, who had a primary or secondary 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:

The Health Board has no data for these products on its pharmacy system.

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).**

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).

Please refer to Q2.

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).

Please refer to Q2.

Question 5.

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

Please refer to Q2.