

Our ref: IG/FOI/FOI.327.25

29 May 2025

Sent via email to: [REDACTED]

Dear [REDACTED]

## Request under the Freedom of Information Act 2000

I write further to your request for information which was received on 15 May 2025, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) partly holds the information that you require.

For ease of reference your request is set out below and my response follows.

### Your Freedom of Information (FOI) Request:

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.

Q1. 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?

Q2. How many patients have been treated in the last 4 months (January to April 2025) 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 (September to December 2024).

Q3. Of the total patients treated in the last 4 months (January to April 2025) with Evrysdi (Risdiplam), please provide the number of patients that were

treated with Spinraza (Nusinersen) in the previous 4 months (September to December 2024).

Q4. Of the total patients treated in the last 4 months (January to April 2025) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (September to December 2024).

Q5. Of the total patients treated in the last 4 months (January to April 2025) with Spinraza (Nusinersen) please provide the number of patients that were treated with Evrysdi (Risdiplam) in the previous 4 months (September to December 2024).

Powys Response:

Q1. From January to April 2025, no patients were admitted with an existing diagnosis of Spinal Muscular Atrophy. Our out-patient data is not coded.

Q2 - Q5. I can confirm that Powys Teaching Health Board (PTHB) does not initiate treatment with any of the medicines listed; patients are treated by providers outside of Powys. PTHB commission services from a number of Welsh health boards and English provider organisations. However in paediatrics, these medications are specialist commissioned by NHS Wales Joint Commissioning Committee (NWJCC) who you may wish to contact via: [nwjcc@wales.nhs.uk](mailto:nwjcc@wales.nhs.uk)

Due to the complex nature of PTHB's commissioning arrangements, not all of our providers indicate the indication for use for each episode of care where these drugs are used. For this reason, PTHB does not hold the data relating to your request, however, the health board is working closely with providers to ensure that this information can be provided in the future. We therefore recommend that you approach our providers for this information directly:

<b>Health Trust/Organisation</b>	<b>FOI Contact Details</b>
Gloucestershire Hospitals NHS Foundation Trust	<a href="mailto:ghn-tr.foi@nhs.net">ghn-tr.foi@nhs.net</a>
Midlands Partnership University NHS Foundation Trust	<a href="mailto:FOI@mpft.nhs.uk">FOI@mpft.nhs.uk</a>
The Robert Jones Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	<a href="mailto:rjah.foi@nhs.net">rjah.foi@nhs.net</a>
Sandwell and West Birmingham NHS Trust	<a href="mailto:swb-tr.SWBH-GM-FOIRequests@nhs.net">swb-tr.SWBH-GM-FOIRequests@nhs.net</a>
The Shrewsbury and Telford Hospital NHS Trust	<a href="mailto:sath.foi@nhs.net">sath.foi@nhs.net</a>
The Royal Wolverhampton NHS Trust	<a href="mailto:rwh-tr.foi@nhs.net">rwh-tr.foi@nhs.net</a>
Worcestershire Acute Hospitals NHS Trust	<a href="mailto:wah-tr.FOI@nhs.net">wah-tr.FOI@nhs.net</a>
Wye Valley NHS Trust	<a href="mailto:Freedom.Information@wvt.nhs.uk">Freedom.Information@wvt.nhs.uk</a>

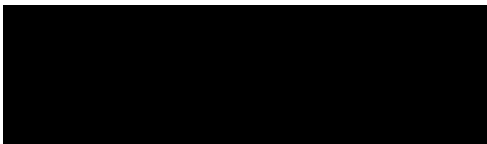
<b>Health Board/Organisation</b>	<b>FOI Contact Details</b>
Aneurin Bevan University Health Board	<a href="mailto:FOI.ABB@wales.nhs.uk">FOI.ABB@wales.nhs.uk</a>
Betsi Cadwaladr University Health Board	<a href="mailto:bcu.foi@wales.nhs.uk">bcu.foi@wales.nhs.uk</a>

Cardiff & Vale University Health Board	<a href="mailto:FOI.Requests@wales.nhs.uk">FOI.Requests@wales.nhs.uk</a>
Cwm Taf Morgannwg University Health Board	<a href="mailto:Freedomofinformation@wales.nhs.uk">Freedomofinformation@wales.nhs.uk</a>
Hywel Dda University Health Board	<a href="mailto:FOI.hyweldda@wales.nhs.uk">FOI.hyweldda@wales.nhs.uk</a>
Swansea Bay University Health Board	<a href="mailto:FOIA.Requests@wales.nhs.uk">FOIA.Requests@wales.nhs.uk</a>
Velindre University NHS Trust	<a href="mailto:Foi.vunhst@wales.nhs.uk">Foi.vunhst@wales.nhs.uk</a>

Under the terms of the Health Board's Freedom of Information procedure, individuals seeking access to recorded information held by the Health Board are entitled to request an internal review of the handling of their requests. If you would like to complain about the Health Board's handling of your request, please contact us directly at the address below or register your complaint via [Powys.FOI@wales.nhs.uk](mailto:Powys.FOI@wales.nhs.uk)

If after Internal Review you remain dissatisfied you are also entitled to refer the matter to the information commissioner at the Information Commissioner's Office (Wales), 2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH. Telephone Number: 0330 414 6421.

Yours sincerely



**Richard Stratton**  
**Assistant Medical Director-Primary Care**

Rydym yn croesawu derbyn gohebiaeth yng Nghymraeg. Byddwn yn ateb y fath ohebiaeth yng Nghymraeg ac ni fydd hyn yn arwain at oedi.

We welcome receiving correspondence in Welsh. We will reply to such correspondence in Welsh and this will not lead to a delay.