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CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg
University Health Board



Freedom of Information Request: Our Reference CTMUHB_276_26

You asked:

Under the Freedom of Information Act, I would like to request the following information and documentation on the below. Please provide a breakdown of the years 2022,2023,2024,2025, Q1 2026.

1. How many patients with epilepsy are there in your health board (please provide a breakdown of gender.)

In completing a search for the information requested, the Health Board has confirmed that this information is not centrally recorded. To retrieve the information requested would require a manual search through individual records.

As this is not information that the Health Board routinely compiles, we would have to carry out a specific exercise to retrieve and collate this data. From our preliminary assessment, we estimate that to comply with this element of your request would exceed the appropriate costs limit under Section 12 (cost of compliance exceeds appropriate limit) of the Freedom of Information Act 2000.

Under the Act there is an allowance of 18 hours, to comply with a request and the cost limit set within the Fees Regulations for this amount of work (18 hours) is £450. The Fees Regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour. The Health Board has therefore relied upon the Section 12 exemption of the Freedom of Information Act 2000 and is refusing your request.

Please note - Patients requiring treatment within this specialty are referred into tertiary Neurology Services of neighbouring Health Boards.

To aid and assist you with your request please see contact details provided below:

Swansea Bay University Health Board - FOIA.Requests@wales.nhs.uk

Cardiff and Vale University Health Board - CAV_FOI.Requests@wales.nhs.uk

2. Of those, how many would be considered at high risk of SUDEP?

Please see response to Q1.

3. How many patients with epilepsy have died during pregnancy? Please give a breakdown of how many of these were due to SUDEP.

We can confirm that the Health Board does not hold this specific information.

The detailed information that you require would be held in the individual's death certificate. Death certificates are not held by the Health Board, but by the Registrar of Deaths (in the local authority). Therefore, you may wish to redirect your request to them directly.

To assist you with this request, the relevant email addresses are provided below:

- Rhondda Cynon Taf County Borough Council - freedomofinformation@rhondda-cynon-taff.gov.uk
- Merthyr Tydfil Borough Council - FOI@merthyr.gov.uk
- Bridgend County Borough Council - foi@bridgend.gov.uk

Some information on deaths is also available on the Office for National statistics. Please see link provided: [Death registration summary statistics, England and Wales - Office for National Statistics](#)

4. Any local risk assessment completed by the Health Board on the implementation of MHRA regulations on Valproate

Following local risk assessment, a Valproate Safety Group (now Teratogenic Medicines Safety Group) was set up to provide guidance, assurance & strategic direction on managing and reducing risks associated with Valproate.

5. Any inclusion of MHRA regulations on Valproate on the Health Board risk register and reports of action taken

An extract has been taken from the risk register and are enclosed as Attachment 1.

6. Any Health Board reports on stakeholder involvement on epilepsy or epilepsy and maternity and whether SUDEP Action included

The Health Board does not hold this information.