



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Freedom of Information Act 2000 - Request Reference FoI/22/175

Clotting Disorders

Information Requested:

Could you please provide answers to the following four questions related to the incidence and treatment of clotting disorders?

1. How many patients has your trust treated (for any medical condition) in the past 3 months with the following drugs:

- **Alphanate** - 0
- **Alprolix** - 6
- **BeneFIX** - 8
- **HaemateP** - 0
- **Idelvion** - <5
- **Refixia** - <5
- **Rixubis** - <5
- **Veyvondi** - 7
- **Voncento** - 5
- **Wilate** - 0
- **Willfact** - 0

2. How many patients have been treated in the past 3 months with:

- **Gene therapy for Haemophilia B ONLY** – 0
- **Desmopressin for Von Willebrand Disease ONLY**

In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 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 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

- **Tranexamic Acid for Von Willebrand Disease ONLY** – Please see above.





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3. Of the patients that were treated with Veyvondi in the past 3 months, how many patients received treatment:

- During surgery - 5
- On-demand to treat bleeding episodes - <5

4. How many patients are registered with your Haemophilia Centre for

- Von Willebrand Disease – adult patients (age 18 or above) - 203
- Von Willebrand Disease – paediatric patients (age 17 or under) - 51
- Haemophilia B (any age) - 54

