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| **Ein cyf / Our ref: 139/20/FOI** |
| **Dyddiad / Date:** 25th August 2020 |

Further to your request for information dated 27th July 2020, I am pleased to provide the following in response to your request. Please accept our sincere apologies for the delay.

**Your request and our response:**

1. **How many adult and paediatric patients registered with your Haemophilia Centre suffer from the following conditions:**

* **Haemophilia A**
* **Haemophilia B**
* **Von Willebrand Disease**

1. **In the last three months, how many patients have been treated with the treatments listed in the table below?**
2. **Of the Haemophilia A patients treated in the last three months, could you please tell us the number of mild, moderate and severe patients.**
3. **Of the Haemophilia A patients treated in the last three months, could you please tell us the number of patients with and without Factor VIII Inhibitors.**
4. **Of the Haemophilia B patients treated in the last three months, could you please tell us the number of mild, moderate and severe patients.**

In accordance with the Freedom of Information Act 2000, this letter acts as a Refusal Notice under section 17 of the Act.

The Health Board does not hold the data in a format that would enable us to fully respond to your request to the level of detail required. However, we are able to advise on how many patients have Haemophilia A, Haemophilia B and Von Willebrand and this is referenced in table 1 provided below. The only way we could identify how many Haemophilia A and Haemophilia B patients are mild, moderate or severe and to also identify how many patients have been treated with DDAVP and Tranexamic acid would be to carry out a specific patient case note review.

Therefore, as this is not information that the Health Board routinely compiles, we would have to carry out a specific exercise to collate this data.  From our preliminary assessment, we estimate that to comply with your particular request would exceed the appropriate costs limit under section 12 of the Freedom of Information Act 2000.  This is currently £450.  In reaching this decision we estimate that it would take staff in excess of 36 hours to locate and review the notes of the 147 patients identified in the tables below. This figure is based on a timescale of 15 minutes per patient case note to review. Therefore, to obtain the data would work out at approximately 36 hours @ £25.00 per hour (cost permitted under the Act) = £900.

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| **Condition** | **Number of Patients** |
| Haemophilia A | 29 |
| Haemophilia B | 4 |
| Von Willebrand | 114 |

Apart from DDAVP and Tranexamic acid, as per our explanation above, we have provided you with the number of patients treated with the other drugs listed in your table:

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| --- | --- |
| **Treatment** | **Number of Patients** |
| Advate | 7 |
| Adynovi | 0 |
| Elocta | 0 |
| Esperoct | 0 |
| Factor Eight Inhibitor Bypass Activity (FEIBA) | 0 |
| Hemlibra | 0 |
| Jivi | 0 |
| NovoEight | 0 |
| NovoSeven RT | 0 |
| Obizur | 0 |
| Refacto AF | 9 |
| Alprolix | 0 |
| BeneFIX | 1 |
| Idelvion | 0 |
| Refixia | 0 |
| Rixubis | 0 |
| Gene therapy (for Haemophilia B) | 0 |
| DDAVP (desmopressin) | Unknown |
| Tranexamic acid | Unknown |
| Veyvondi | 0 |
| Voncento | 18 |
| Wilate | 0 |

Under our obligation to advise and assist we can also confirm that the use of haemophilia products is managed by the Commercial Medicines Unit (CMU). The CMU currently manage a UK wide procurement of coagulation products. National usage is collated by the National Haemophilia database through the UK Haemophilia Directors Organisation (UKHCDO) and is on a centre by centre basis. The data is published by the UKHCDO in a report entitled UK National Haemophilia Database Bleeding Disorder Statistics and under our obligation to advise and assist we have provided a link below to the UKHCDO website.

<http://www.ukhcdo.org/annual-reports/>

There is also a Wales only version of this data which is accessible by contacting the administrator to the UKHCDO, their contact details are:

Ms Lynne Dewhurst,

Administrator to the UKHCDO

City View House

5 Union Street

Ardwick

Manchester

M12 4JD

Tel: 0161 277 7991

Email: [support@ukhcdo.org](mailto:support@ukhcdo.org)